DOCUMENT RESUME

ED 104 084	EC 071 945
AUTHOR	Halpern, Andrew S.; And Others
TITLE	A Planning and Evaluation Strategy for State Developmental Disabilities Councils: Progress Report. Working Paper No. 71.
INSTITUTION	Oregon Univ., Eugene. Rehabilitation Research and Training Center in Mental Retardation.
PUB DATE	Aug 73
NOTE	164p.
EDRS PRICE	MF-$0.76 HC-$8.24 PLUS POSTAGE
DESCRIPTORS	Exceptional Child Services; Handicapped Children; *Models; *State Programs; *State Surveys; *Workshops
IDENTIFIERS	*Developmental Disabilities; Oregon

ABSTRACT

Presented in the first year report of a joint project by the Oregon Developmental Disabilities Council and the Research and Training Center in Mental Retardation at the University of Oregon are planning strategies to assist state advisory councils in serving the developmentally disabled. Described in part one are project activities and reproduced in part two are training materials to explain the proposed strategies. Reviewed are such project aspects as components (including education and social services) of annual state plans and models of programing-planning-budgeting systems. A discussion of project methodology and results centers on findings from state workshops and surveys regarding such major responsibilities as assessing state needs and monitoring on-going programs and projects. Summarized is the project's progress and outlined are second year activities. Instructional materials presented include the script of a slide-tape show illustrating a planning and evaluation strategy for state developmental disabilities councils, and procedures and exercises for workshops on defining goals and priorities and evaluating goal achievement by state and local councils. Two appendixes present such information as a list of 11 expanded problem statements adopted by the Oregon State Council for use in the state plan. (CL)

ED104084

EC071945

U.S. DEPARTMENT OF HEALTH
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
EDUCATION
THIS DOCUMENT HAS BEEN REPRODUCED EXACTLY AS RECEIVED FROM THE PERSON OR ORGANIZATION ORIGINATING IT. POINTS OF VIEW OR OPINIONS STATED DO NOT NECESSARILY REPRESENT OFFICIAL NATIONAL INSTITUTE OF EDUCATION POSITION OR POLICY

College of Education
Department of Special Education

Rehabilitation Research and Training Center in Mental Retardation

University of Oregon, Eugene

ED10408

WORKING PAPER NO. 71

A Planning and Evaluation Strategy for State Developmental Disabilities Councils: Progress Report

Andrew S. Halpern, Kenneth D. Fox, and
John M. Nagle

August, 1973

PREFACE

The information contained in this report represents an initial effort to answer an intriguing question: How can an advisory council effectively influence the operation of programs and agencies over which it possesses relatively little fiscal control? More specifically, this question is raised within the context of a state planning and advisory council for developmentally disabled citizens. The question emerged in reaction to a federal mandate that such councils be responsible for statewide planning and evaluation of services for developmentally disabled people, even though these councils administer only a very small proportion of the dollars that are spent for such services throughout the state.

In an attempt to implement this mandate concerning planning and evaluation, the Oregon Developmental Disabilities Council and the Research and Training Center in Mental Retardation at the University of Oregon have collaborated on a Federally supported project to design an effective planning and evaluation strategy that might be used by developmental disabilities councils throughout the country. The first year of this project, which is the subject of the present report, showed progress in implementing the planning part of the strategy. Next year's effort will be concentrated on evaluation activities.

Part One of this report describes project activities, and Part Two reproduces training materials that have been developed to assist developmental disabilities council members in understanding the proposed strategy. The appendices include materials that were produced by the Oregon Council in the course of implementing the strategy.

The staff of this project are particularly grateful to a number of people for their invaluable assistance throughout the past year. Members of the Oregon Council, while never reluctant to offer constructive criticism, have always been highly supportive of our efforts. The staff of the Oregon Council, especially Mr. David Porter, have provided us with assistance in many areas, and next year Mr. Porter will be devoting half of his time to this project at Council expense. Dr. Terry Eidell helped us greatly in conceptualizing the strategy and working toward its implementation through a series of workshops. And finally, we are most grateful to Sharon Babic and Julie Pryor for attending to the many details of the day to day project administration.

A.S.H.
K.D.F.
J.M.N.

TABLE OF CONTENTS

PART I - Report of Project Activities

Section 1 - INTRODUCTION.. 1
Background Information.................................... 1
Statement of the Problem.................................. 2
A Promising Source of Ideas............................... 3
Project Objectives.. 5
References.. 9

Section 2 - METHODOLOGY AND RESULTS............................ 10
Strategy Development Activities........................... 10
Needs Assessment, Goal Definition, and Priority Setting Activities.. 12
Monitoring On-Going Programs and Projects................. 27
Management and Program Evaluation......................... 27

Section 3 - SUMMARY, DISCUSSION, AND FUTURE ACTIVITIES....... 30
Summary of Progress....................................... 30
Project Activities for the Second Year.................... 31

PART II - Instructional Materials

Section 1 - SCRIPT OF A SLIDE-TAPE PRESENTATION ILLUSTRATING A PLANNING AND EVALUATION STRATEGY FOR STATE DEVELOPMENTAL DISABILITIES COUNCILS.............................. 33
Script from the Presentation.............................. 33

Section 2 - ONE WAY TO INVOLVE A LOCAL COMMITTEE IN DEFINING GOALS AND PRIORITIES FOR THE DEVELOPMENTALLY DISABLED.... 43
Introduction.. 43
The Concepts Underlying the DAP Group Processes.......... 44
An Overview of the DAP Processes for Identifying Local Needs of the Developmentally Disabled................ 46
Notes to a Workshop Trainer............................... 48

Section 3 - A DESCRIPTION OF SURVEY PROCEDURES FOR IDENTIFYING STATEWIDE AND/OR LOCAL NEEDS OF THE DEVELOPMENTALLY DISABLED.. 66
Introduction.. 66
Implementation of the Needs-Assessment Survey............ 67
An Illustration of the Expanded Problem-Statement Clustering Process.................................. 72

TABLE OF CONTENTS (continued)

Section 4 - TWO ALTERNATIVE WAYS TO INVOLVE A STATE DD COUNCIL IN DEFINING STATEWIDE GOALS AND PRIORITIES FOR DEVELOPMENTALLY DISABLED CITIZENS........................994
    Alternative One.. 94
    Alternative Two.. 95
    Modifying or Refining an Existing Set of Statewide Goals and Priorities.. 97

Section 5 - ROLE OF THE STATE DEVELOPMENTAL DISABILITIES COUNCIL IN EVALUATING ACHIEVEMENT OF ITS GOALS............ 98
    Background and Context.. 98
    Implementation of the Strategy.. 98
    Some Simulation Exercises..102
    Exercise One..104
    Exercise Two..106
    Exercise Three..107

APPENDIX A

Developmental Disabilities Planning and Advisory Council Membership..108
State Council September Workshop Agenda......................110
State Council April Workshop Agenda............................111

APPENDIX B

Materials Developed to Assist the State Council in Their Needs Assessment and Goal Setting Activities..............112
A Complete List of the Eleven Expanded Problem Statements Adopted by the Oregon State Council for Use in the State Plan..133

Part I

Report of Project Activities

INTRODUCTION

Background Information

On Friday, October 30, 1970, President Nixon signed into law the Developmental Disabilities Services and Facilities Construction Act (Public Law 91-517). This legislation, which significantly expanded the scope of the Mental Retardation Facilities Construction Act of 1963, was designed to provide states with broad responsibility for planning and implementing a comprehensive program of services for developmentally disabled citizens. Moreover, the new legislation authorized a formula-grant program to stimulate the construction of facilities and the provision of services for all persons with developmental disabilities, thereby broadening considerably the scope of earlier programs by including not only the mentally retarded but also those suffering from cerebral palsy, epilepsy, and other neurological handicapping conditions.

Current statistics from the Department of Health, Education and Welfare estimate that 8.7 million children and adults in the United States suffer from developmental disabilities. Of this number, approximately six million are mentally retarded, one million are epileptics, 700,000 suffer from cerebral palsy, and one million are affected with other neurological handicaps originating in childhood, but excluding blindness or deafness. Moreover, it is unfortunately common for severely developmentally disabled individuals to suffer from two or more debilitating conditions. In general, the more serious the disability, the more likely it is that the afflicted individual will be multiply handicapped.

In order to receive federal aid under this program, each state must establish a planning and advisory council that can prepare and evaluate annually a comprehensive state plan for meeting the needs of its developmentally disabled citizens. Each annual plan must describe:

1. The current status of statewide facilities and services for the developmentally disabled, including the quality, extent, and scope of those services provided under the following federally assisted programs:

    a. Education for the handicapped
    b. Vocational rehabilitation
    c. Public assistance
    d. Medical assistance
    e. Social services

   f. Maternal and child health
   g. Crippled children's services
   h. Mental health and mental retardation programs
   i. Other related programs the council deems necessary

2. The methods that will be used by the state to assess how effectively it is currently meeting the needs of individuals with developmental disabilities, including:

   a. a definition of the population to be served, with appropriate baseline information;
   b. a determination of needs; and
   c. a description of each service program and the procedures for evaluating its accomplishments.

3. The policies and procedures that will be employed by the state as it expends funds made available under the Act, including its designation of priorities for allocating such funds.

In addition to carrying out the above responsibilities, the state planning and advisory council must inform its public about current services and facilities available to developmentally disabled people; it must develop general planning and program policies for such services; and it must stimulate local planning to assure coordination of all program activities.

Statement of the Problem

Within this broad range of responsibilities, the mandate to state DD councils with respect to evaluation is especially far reaching and complex. Each council is required to evaluate how well existing services meet the needs of developmentally disabled citizens throughout the state. This overall task clearly requires several intermediate steps. The needs of the developmentally disabled must be ascertained from both local and statewide perspectives. The prevalence of the developmentally disabled must be determined, and an inter-agency format for reporting data must be developed to facilitate evaluation of client services. A strategy must also be developed and implemented to integrate these various tasks. And finally, since the usefulness of any strategy depends upon how well it is understood, training procedures and materials must be developed that will acquaint council members with both the strategy and their role in its implementation.

The basic purpose of this project, therefore, has been twofold: (1) to investigate a strategy that can be employed by state developmental disabilities councils to meet their responsibilities with respect to planning and evaluation; and (2) to develop and field test training procedures that can be used by councils to acquaint themselves with this strategy.

A Promising Source of Ideas

Nearly all of the requirements placed upon state developmental disabilities councils reflect their need for systematic procedures for identifying needs, evaluating programs, and allocating resources on the basis of well-developed data systems. Developing some form of a planning-programming-budgeting system (PPBS), therefore, seemed to be the most useful way to help councils meet their challenge. The relevance of PPB systems to the needs of such councils is evident from the literature (see, for example, Lyden and Miller [1968], and Novick [1965]), especially from the field of public education, where forms of PPBS have been applied in operational settings that are quite similar to those of a state developmental disabilities council.

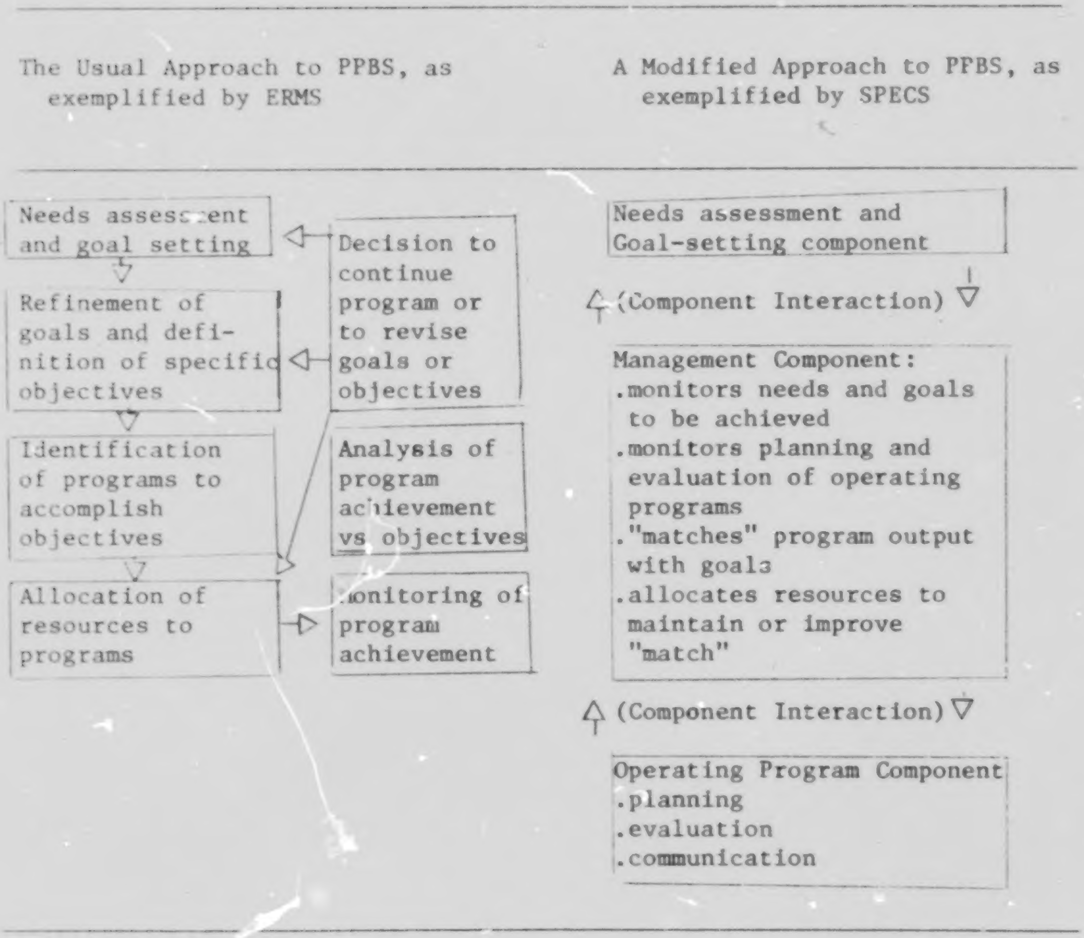
Careful review of this literature reveals, however, that the same model does not underlie all educational PPB systems. Some, for instance, are based on the original PPBS model developed in industry and then later employed in the federal government; e.g., ERMS (Educational Resource Management System), developed by the Research Corporation of the Association of School Business Officials (Curtis, 1971). Other PPB systems designed for public schools are based on a somewhat different concept; e.g., SPECS (School Planning, Evaluation, and Communication System) developed at the Center for the Advanced Study of Educational Administration, University of Oregon (Eidell and Nagle, in press).

The first of these approaches to PPBS defines a clearly linear flow of organizational decision-making starting with the identification of needs or goals, moving through their refinement, and resulting eventually in prescriptions for specific operating programs and specific performance objectives within each program. Subsequent evaluation of the achievement of performance objectives provides management with input for revising either goals or operating programs.

The second approach to PPBS involves three non-linear components or activities in which decision-making is not centrally controlled. One of these components is concerned with assessing an organization's needs and defining its goals. A second component focuses on planning and evaluating within the organization's operating programs. The third component monitors the outcome of the other two components continuously in an effort to maintain, by influencing resource allocations, the best possible "match" between the organization's needs or goals and the outcomes of its operating programs. Figure 1 depicts these two different approaches to PPBS.

Figure 1

Comparison of the Two Fundamental Models of PPBS


The Usual Approach to PPBS, as exemplified by ERMS
A Modified Approach to PPBS, as exemplified by SPECS
Needs assessment and goal setting
Refinement of goals and definition of specific objectives
Identification of programs to accomplish objectives
Allocation of resources to programs
Decision to continue program or to revise goals or objectives
Analysis of program achievement vs objectives
Monitoring of program achievement
Needs assessment and Goal-setting component
(Component Interaction)
Management Component:
.monitors needs and goals to be achieved
.monitors planning and evaluation of operating programs
."matches" program output with goals
.allocates resources to maintain or improve "match"
(Component Interaction)
Operating Program Component
.planning
.evaluation
.communication

Further analysis of these two approaches and their origins suggests that the usual PPBS model is particularly applicable to organizations in which management is highly centralized and has authority not only to regulate, but to define and implement particular programs. By contrast, the SPECS model seems most applicable to organizations in which management has responsibility for coordinating programs with needs, but lacks absolute authority over what actually occurs in those programs. In such organizations, management can influence operating programs only indirectly by providing hard data on the discrepancies which exist between identified needs and current program outcomes.

A state developmental disabilities council closely approximates the role of management in this second, modified approach to PPBS. Although the SPECS training materials have not been directly applicable to council activities, for they are designed specifically for public schools, the basic concepts underlying those materials have been extremely useful throughout this project, and the SPECS operational documents have provided an excellent point-of-departure in our development of training materials and procedures for state and local DD councils.

Project Objectives

Exploring the feasibility of a PPB system for DD councils and developing effective training procedures for members of those councils could not have been accomplished in a vacuum. We were therefore extremely grateful for the opportunity to collaborate throughout the year with the Oregon Developmental Disabilities Council in translating the modified PPBS model into a strategy for planning and evaluation as well as a set of training procedures and materials. More specifically, we have worked to achieve the following seven objectives.

1. The Oregon Developmental Disabilities Council will become aware of its role with respect to evaluation and involved in the implementation of this role.

2. The state council will identify, delineate, and prioritize its own perceptions of the needs of the developmentally disabled in Oregon.

3. Local developmental disabilities committees will identify, delineate, and prioritize their perceptions of the needs of the developmentally disabled in their localities.

4. Local needs of the developmentally disabled will be assessed in terms of the opinions of practitioners who are

serving the developmentally disabled in various public and private agencies.

5. The state council will arrange for the development of a standardized format for establishing a common data base that can identify and track the services that are being provided to the developmentally disabled in Oregon.

6. The state council will arrange for the development of a format for evaluating the effectiveness of projects that are funded in accordance with the developmental disabilities state plan.

7. The state council will begin to exert its managerial role with respect to systematic program evaluation.

Project Setting

Oregon ranks tenth among the states in total area (96,981 square miles) spanning 395 miles from east to west and 295 miles from north to south. Its outstanding geographic feature is the Cascade Mountain range, which runs north and south for the length of the state 100 miles inland from the Pacific Ocean. The area west of the mountains has a generally moderate climate and is well supplied with water. The remainder of the state, comprising approximately two-thirds of its total area, experiences greater extremes of climate and has many arid regions. Approximately two-thirds of the state's current population of 2.1 million residents live in urban environments, Portland and Eugene-Springfield being the largest of these areas. Most of Oregon's residents live in the western third of the state, between the Cascades and the Coast Range.

With respect to developmentally disabled citizens in Oregon, the following prevalence estimates have been calculated by applying national prevalence rates per thousand to the 1970 Oregon Census data (State of Oregon Comprehensive Developmental Disabilities Plan, 1972):[1]

---

[1] These particular data represent low estimates of published prevalence ranges; other data available vary by as much as 30,000 individuals, particularly with respect to the prevalence of mental retardation in the state.

1. Cerebral Palsy -- 6,251
2. Epilepsy -- 10,452
3. Mental Retardation -- 37,039

Comparing these prevalence estimates with available data on agency services to developmentally disabled clients, the 1972 State Plan states "that approximately 70% of the developmentally disabled in Oregon are either undiagnosed or receive no specialized services" (p. 54).

Within the state, those agencies directly responsible for administering the state developmental disabilities plan include the Comprehensive Health Planning Authority and the State Mental Health Division. Comprehensive Health Planning, which is concerned with all health-related activities in the state, is the designated planning agency; the Mental Retardation Services Section of the State Mental Health Division is the designated agency for administering special construction and service projects funded by the Developmental Disabilities legislation.

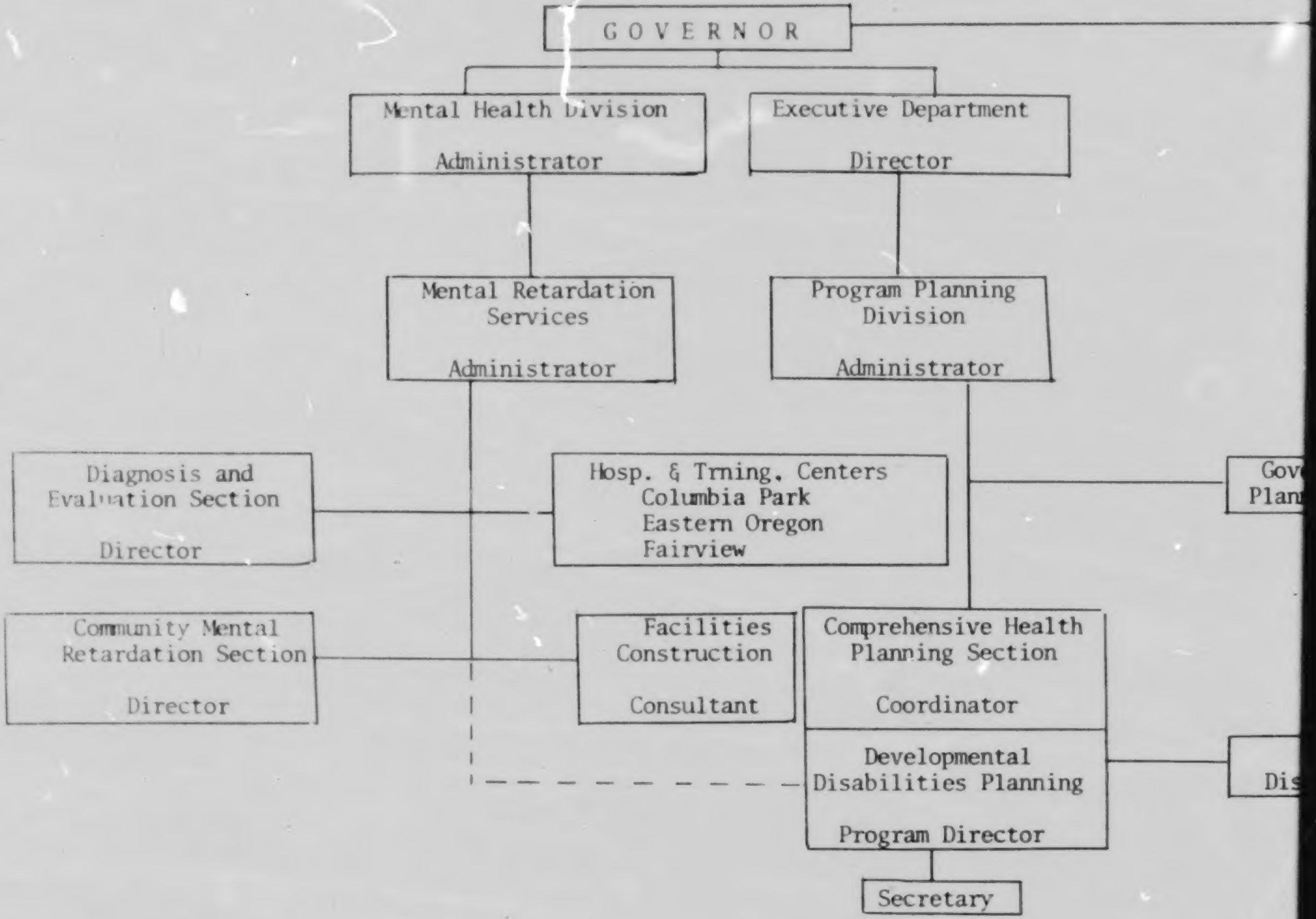

GOVERNOR
Mental Health Division
Administrator
Executive Department
Director
Mental Retardation Services
Administrator
Program Planning Division
Administrator
Diagnosis and Evaluation Section
Director
Hosp. & Trning. Centers
Columbia Park
Eastern Oregon
Fairview
Gov
Plan
Community Mental Retardation Section
Director
Facilities Construction
Consultant
Comprehensive Health Planning Section
Coordinator
Developmental Disabilities Planning
Program Director
Dis
Secretary

Figure 2
Administration of the
Developmental Disabilities Act
in Oregon

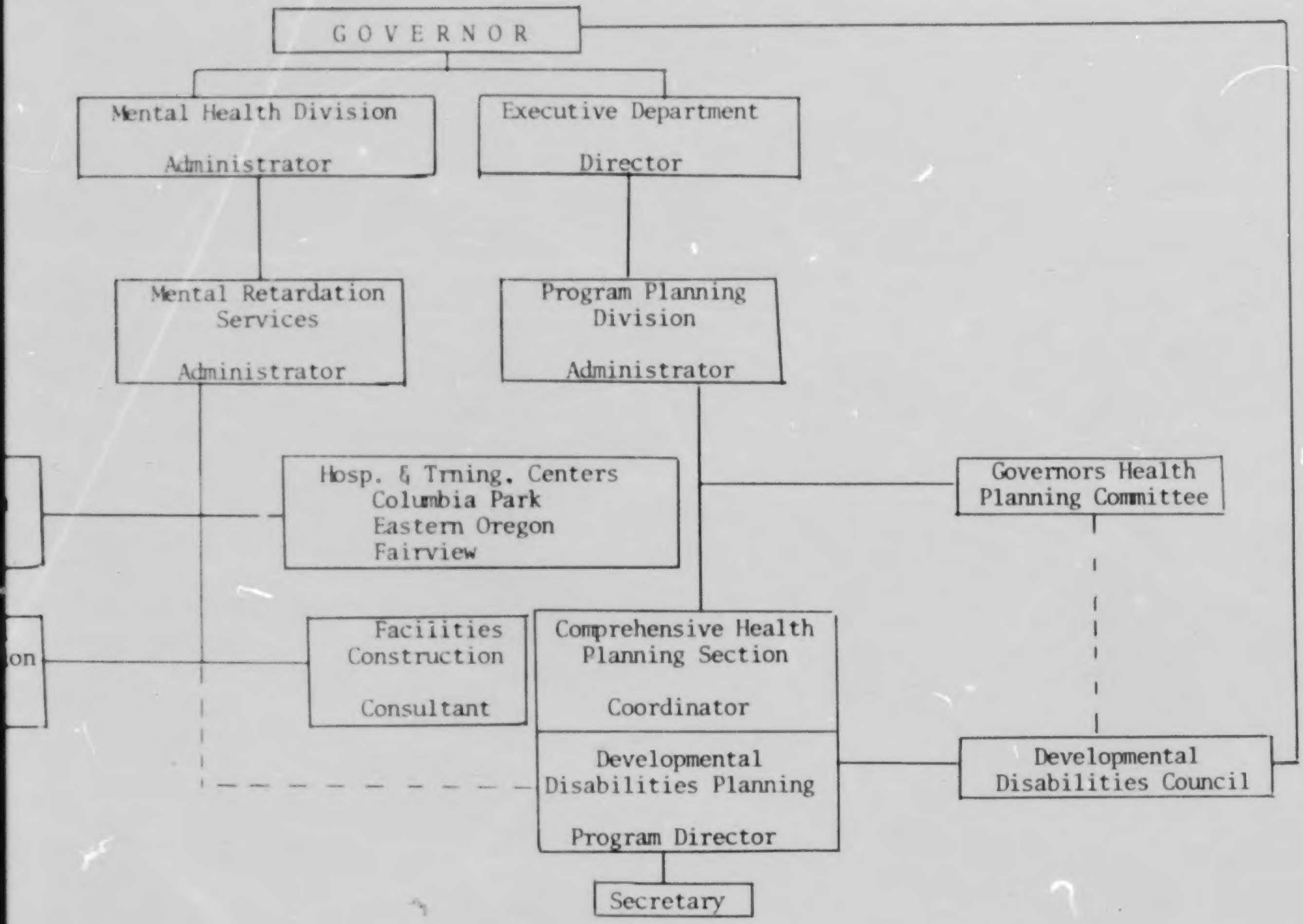

GOVERNOR
Mental Health Division
Administrator
Executive Department
Director
Mental Retardation Services
Administrator
Program Planning Division
Administrator
Hosp. & Trning. Centers
Columbia Park
Eastern Oregon
Fairview
Governors Health Planning Committee
on
Faciiities Construction
Consultant
Comprehensive Health Planning Section
Coordinator
Developmental Disabilities Planning
Program Director
Developmental Disabilities Council
Secretary

Figure 2
Administration of the
Developmental Disabilities Act
in Oregon

References

Brissey, F. L., & Nagle, J. M. Final report on the DAP joint problem-solving process. Eugene, Oregon: Center for Advanced Study of Educational Administration, University of Oregon, 1973.

Curtis, W. Educational resources management system. Chicago: Research Corporation of the Association of School Business Officials, 1971.

Eidell, T. L., & Nagle, J. M. SPECS orientation workshop materials and the SPECS in-depth training materials. Washington, D. C.: General Learning Corporation, 1973.

Lyden, F. J., & Miller, E. G. (Eds.). Planning-programming-budgeting: A system approach to management. Chicago: Markham Publishing Company, 1968.

Novick, D. (Ed.). Program budgeting. Cambridge, Mass.: Harvard University Press, 1965.

Department of Human Resources, Health Division, Office of Comprehensive Health Planning. State of Oregon comprehensive developmental disabilities plan. Salem, Oregon: Department of Human Resources, 1972.

METHODOLOGY AND RESULTS

The seven objectives of this project were approached through a series of activities that included two workshops for Oregon's state developmental disabilities council, individual workshops for three of the state's local developmental disabilities committees, and a statewide survey of practitioners and experts in the field of developmental disabilities. Furthermore, these various activities, and the project objectives related to each, were organized into four major activity clusters reflecting the SPECS model of PPBS:

1. Overall Strategy for Planning and Evaluation.

   Objective 1: State council awareness of and involvement with its evaluation role.

2. Assessing Needs, Defining Goals, and Setting Priorities.

   Objective 3: Local committees' ranking of needs in their communities.

   Objective 4: Practitioner assessment of local needs.

   Objective 2: Council's statewide ranking of needs.

3. Monitoring On-Going Programs and Projects.

   Objective 5: Development of format to track services to developmentally disabled people.

   Objective 6: Development of format for evaluating developmental disabilities formula-grant funded projects.

4. Management and Program Evaluation.

   Objective 7: Development of council's management role in program evaluation.

Strategy Development Activities

As indicated earlier, the major goal of this project was to develop and pilot-test an overall strategy that will help state councils monitor and evaluate the effectiveness of on-going programs and activities for developmentally disabled people. More specifically, an attempt has been made to adapt a particular model of PPBS developed for schools to the special needs of a state DD council. Once developed, the model was then presented and pilot-tested with the Oregon DD Council. Accomplishment of the project's first objective involved five activities: (a) adaptation of the SPECS model of a PPB system, (b) conducting an initial workshop for the Oregon state developmental disabilities council, (c) development of an initial set of instructional materials, (d) conducting a second workshop for the Oregon council, and (e) revision of the instructional materials.

Development of the Overall Strategy

Development of a modified PPB system for a state DD council, including development of procedures and materials to explain it, began in July and August 1972. After reviewing the literature related to planning and evaluation and studying the organizational and informational needs of a state council for the developmentally disabled, basic PPBS concepts were translated into a strategy that spoke directly to the needs of a state DD council.

Oregon's State Council September Workshop

The first of two workshops for the Oregon state developmental disabilities council was held near Bend, Oregon, on September 14-16, 1972. After presenting our initial design for an evaluation strategy, feedback was sought on both the content of the strategy and our plans for the remainder of the project year. It was important to know, for example, whether the strategy addressed adequately all of the council's informational needs. Council members were also asked for suggestions concerning how to refine the procedures and materials that had been used to explain the strategy. And, perhaps most important, council support for implementing the strategy during the remainder of the year was requested and obtained. Nineteen members of the Oregon Council attended the workshop. (See Appendix A for detailed information about workshop's participants and its agenda of activities.)

Reactions to the workshop's activities were generally positive. Most participants found the topics informative and relevant, and regarded the discussion sessions and small-group exercises as particularly helpful in promoting a common awareness of the council's needs with respect to planning and evaluation. Reactions to the strategy itself were especially useful, suggesting simplification in some areas, but also elaboration upon the methods which a developmental disabilities council might use to effect change in service delivery patterns to clients.

Initial Development of Instructional Materials

On the basis of the reactions received during the September workshop, the basic strategy was revised and an initial set of training materials was developed for explaining the refined strategy to members of a DD council. Based upon positive experience with handouts and transparencies during the September workshop, it seemed that a slide-tape presentation would be the most effective and efficient way to provide groups with an initial overview of the strategy. Accordingly, a narration explaining the strategy and an accompanying set of slides were developed in preparation for the second workshop for Oregon's State Council.

The April Workshop for Oregon's State Council

This workshop was held on April 13-14, 1972, in order to share our revisions of the strategy and our newly developed instructional materials with the Oregon State Council. Most who attended the first workshop also attended this second one, and their reactions and comments proved to be particularly helpful as a foundation for revising the slide-tape presentation. For example, they indicated clearly that the 40 minute length of the presentation would have to be shortened greatly in order to arouse the interest and involvement of trainees.

Final Revision of Instructional Materials

Incorporating feedback from the April workshop participants and from project staff, the slide-tape presentation was further revised and shortened during May and June of 1973. The final slide-tape kit is now available to other developmental disabilities councils from the director of this project. Its script is included in Part Two of this report.

Needs Assessment, Goal Definition, and Priority Setting Activities

A state developmental disabilities council of twenty to thirty people should not have sole responsibility for identifying needs and formulating goals and priorities for all developmentally disabled individuals in its state. Just as important as the views of state council members are the views of regional developmental disabilities committee members, practitioners in the field, and developmentally disabled people themselves. Therefore, as part of this project, both survey and workshop procedures have been developed and pilot-tested for obtaining each of these various points of view.

The September Workshop for Oregon's State Council

During the September workshop, council members were introduced to an initial series of procedures that had been designed to assess needs and set goals at both regional and state levels. Workshop participants were also asked to simulate the procedures by identifying what they then considered to be the most critical needs of developmentally disabled people in Oregon.

After dividing into three small groups, participants were asked to generate answers to the question, "What do you regard as the most important goals to be achieved for developmentally disabled people in Oregon?" For each goal, participants were asked to indicate a referent or topic that was specifically related to a service or problem area, and then to generate a statement about that referent describing some preferred condition. As participants generated these goal statements, they were recorded on large newsprint sheets.

Within these same small groups, participants were next asked to examine each of the generated goal statements for clarity. Any statement that was not understandable was discussed, paraphrased, and revised until its author's meaning was clear to others in the group. All of the goal statements were then collated and a single list of "related goal-sets" was developed and presented to the total council. Council members were invited to rate the importance of each goal statement, and the ten most important goal statements were rank-ordered from first to tenth.

Although some problems were uncovered that later required modification of these goal-setting procedures, council members reacted quite positively to them and gave approval to their continued use -- with three regional committees and again with the state council later in April.

Goal-Setting Workshops for Three Regional Committees

In November, December, and January, 1973, goal-setting workshops were conducted for regional DD committees that were established in three of Oregon's fourteen local administrative districts of the Oregon Comprehensive Health Planning Authority. Figure 3 indicates all fourteen districts and highlights the three that were involved. The workshops were conducted in Portland, Eugene, and Bend.

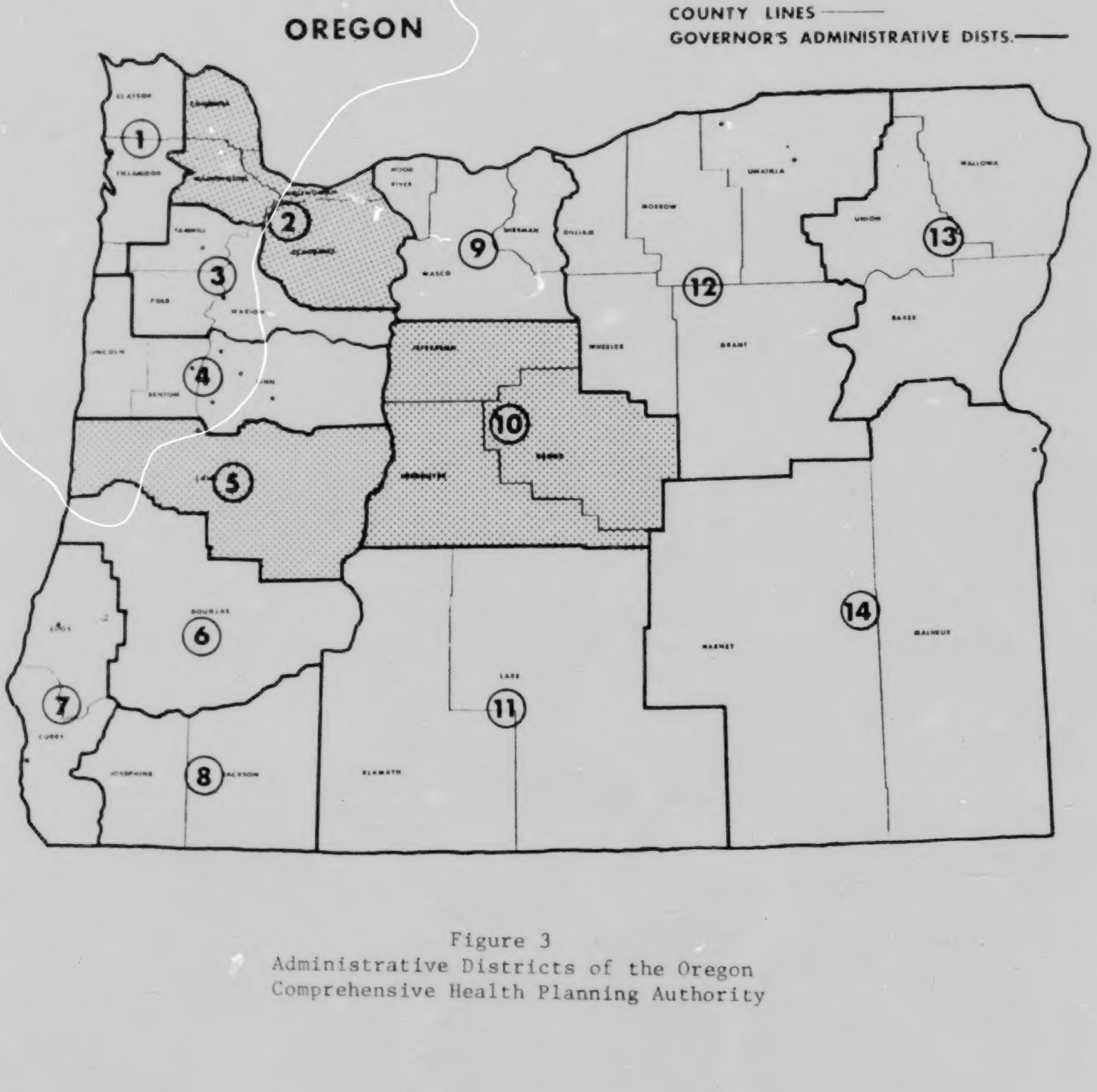

OREGON
COUNTY LINES
GOVERNOR'S ADMINISTRATIVE DISTS.
CLATSOP
TILLAMOOK
YAMHILL
POLK
MARION
LINCOLN
BENTON
LINN
HOOD RIVER
WASCO
SHERMAN
GILLIAM
MORROW
UMATILLA
UNION
WALLOWA
BAKER
GRANT
WHEELER
DOUGLAS
COOS
CURRY
JOSEPHINE
JACKSON
KLAMATH
LAKE
HARNEY
MALHEUR
1
2
3
4
5
6
7
8
9
10
11
12
13
14

Figure 3
Administrative Districts of the Oregon
Comprehensive Health Planning Authority

The purpose of these workshops was two-fold: (1) to provide local, grass-roots perceptions of the needs of developmentally disabled people to the state developmental disabilities council; and (2) to stimulate the organization of permanent local committees that could coordinate services for developmentally disabled people and reduce service gaps at a local level.

To the extent possible, the three local committees were organized in accordance with Oregon's guidelines for the state developmental disabilities council which suggest:

1. At least 51% consumers (i.e., nonproviders) of services.

2. A minimum of 15 members.

3. Representatives from each of the following provider agencies:

   a. Special Education
   b. Vocational Rehabilitation
   c. Maternal and Child Health
   d. Community Mental Retardation
   e. Public Welfare
   f. Children's Services
   g. Crippled Children's Division

4. Two representatives from each of the following groups:

   a. Epilepsy League of Oregon
   b. United Cerebral Palsy Association
   c. Oregon Association for Retarded Children

5. Two consumer representatives.

6. Additional consumer or provider representatives so long as a consumer majority was maintained.

In each region, the selection of committee members was coordinated by the local Comprehensive Health Planning staff. As indicated in Table 1, two of the three committees failed to achieve the desired balance between consumers and providers.

To identify and assign priorities to regional goals for developmentally disabled people, the three regional committees employed a set of procedures similar to those employed by the state council during the September workshop. Some steps in the process were modified on the basis of past experience, but the basic process remained essentially common to all four groups.

Table 1

Data on Selection of Participants for Regional Workshops

Regional Committee	Coordinators and Assistants in Participant Selection	Number of Participants Providers	 Consumers	 Total	Worksh Locati and Dates
Region 2	Hazel Warren (Metro-Portland CHP staff) David Porter (State DD Council staff)	15	13	28	Portl (Rama Jan.
Region 5	Lucille Russell (Lane Co. Mental Health) Tom Nugent (Lane Co. Mental Health)	18	11	29	Cotta (Vill Dec.
Region 10	Russell Reeck (CHP staff) Art Tassie (Central Oregon Opportunity Center)	13	15	28	Bend (Sunr Nov.

Table 1

Data on Selection of Participants for Regional Workshops

Coordinators and Assistants in Participant Selection	Number of Participants			Workshop Location and Dates
	Providers	Consumers	Total	
Hazel Warren (Metro-Portland CHP staff)	15	13	28	Portland (Ramada Inn) Jan. 5-6, 1973
David Porter (State DD Council staff)				
Lucille Russell (Lane Co. Mental Health)	18	11	29	Cottage Grove (Village Green) Dec. 15-16, 1972
Tom Nugent (Lane Co. Mental Health)				
Russell Reeck (CHP staff)	13	15	28	Bend (Sunriver) Nov. 10-11, 1972
Art Tassie (Central Oregon Opportunity Center)				

1. Workshop participants met in small groups to address the question, "What do you consider to be the most important problems faced either by developmentally disabled individuals you know personally or by most developmentally disabled people in your particular region of the state?" Each group formulated its answers in the form of a referent and comparable statements of "what is" and "what is preferred" regarding each referent.

2. Working in the same small groups, participants rated each problem-statement for clarity. Based on these individual ratings, group members discussed, paraphrased, and revised each problem-statement so that it was clear both to members of that group and to at least one of the workshop's staff members.

3. Workshop staff then collected the individual problem-statements and, by combining related statements and deleting redundancies, developed a series of "expanded problem-statements." (For an illustration of the procedure used to develop these "expanded problem-statements," see Part II, Section Two of this report.)

4. The expanded problem-statements were then presented to the total committee and rated and discussed with respect to their clarity, truth, and accuracy of collation. In effect, participants were asked to develop a shared understanding of the cumulative list. As revisions were necessary, they were of course made.

5. Finally, each participant was asked (a) to rate each of the final problem-statements for importance and (b) to rank-order the most critical of them.

Each local committee member left the workshop with two products: (1) a list of the ten or twelve most critical problems faced by developmentally disabled people in that region and rank-ordered in priority; and (2) a list of all of the problem-statements generated, each rated for importance. (A summary of the first of these products can be found in Appendix B.)

A Survey of Practitioners and Experts

To determine the needs of developmentally disabled people as perceived by those who did not participate in local committee workshops, a statewide survey was conducted of practitioners and experts throughout Oregon. The survey had a two-fold purpose: (1) to orient practitioners and experts across the state to the need for clear goals to help direct the state council; and (2) to provide the state council with information about the major problems of the developmentally disabled within each region of the state and within the three major disability groups. Those who participated in the survey included providers of services to developmentally disabled clients and nominated experts in each of the three main disability categories.

To identify the first group, two kinds of information were sought from the eight state-supported agencies in Oregon that provide services to the developmentally disabled: (1) a list of personnel known to be providing services, and/or (2) a list of agencies, branch offices, etc., where personnel supervisors could be asked to identify providers of services. Those who had caseloads of at least 20% developmentally disabled clients and who expressed a willingness to participate became the survey's "provider" population. They numbered 262 practitioners and, as Table 2 indicates, represented all eight state agencies. Each participant was contacted by telephone, briefly informed of the nature of the survey, and asked if he would be willing to participate.

To identify the "expert" population, the three major relevant private organizations in Oregon (Oregon Association for Retarded Children, United Cerebral Palsy Association, Epilepsy League of Oregon) provided us with the names of 20 to 25 people whom they considered expert in their knowledge about developmentally disabled people. Once again, the individuals identified were contacted by telephone and sixty-eight agreed to participate. Table 3 summarizes the composition of this group and indicates a fair balance of experts representing the three major disabilities.

Due to the uneven distribution of practitioners across the state of Oregon, it became necessary to collapse Oregon's fourteen regions into five for purposes of the survey. To identify these five, total population estimates were considered, as well as distribution of the state's practitioners, availability of services within regions, and proximity to service centers. Figure 4 indicates the five survey regions that evolved; Table 4 indicates the representation of practitioner groups in each of the survey regions.

Table 2

Selection Procedures Employed to Identify Respondents Representing the Provider Population

Occupational Group	State Contact	No. of Individuals Referred by State Office (N)	No. of Branch Offices Referred by State Office (N)	No. of Branch Offices Contacted (N)	Special Selection Considerations
A. Vocational Rehabilitation	Terry James	23*	--	--	--
B. Work Activity Centers	Robert Shook	--	25	23	--
C. Mental Health Clinics	Robert Shook	--	29	27	--
D. TMR Ed., Services	Robert Shook	--	30	26	(1) see next page
E. Special Education	Ray Rothstrom	450	--	--	(2)
F. Public Welfare	William Lowther	--	35	34	--
G. Child Develop., Clinics	Rhesa Penn	23	--	--	--
H. Children's Services	Dean Orton	9*	--	--	(3)

Table 2

Selection Procedures Employed to Identify Respondents Representing the Provider Population

State Contact	No. of Individuals Referred by State Office (N)	No. of Branch Offices Referred by State Office (N)	No. of Branch Offices Contacted (N)	Special Selection Considerations	Participants Selected (N)
Terry James	23*	--	--	--	23
Robert Shook	--	25	23	--	26
Robert Shook	--	29	27	--	33
Robert Shook	--	30	26	(1) see next page	48
Ray Rothstrom	450	--	--	(2)	53
William Lowther	--	35	34	--	53
Rhesa Penn	23	--	--	--	17
Dean Orton	9*	--	--	(3)	9
					262

(Continuation of Table 2)

*Original contacts and agreements to participate were handled by the state office.

(1) One additional selection procedure was employed for this group. In an attempt to provide a representative sampling of each school district, the district contact person was requested to provide the name of at least one teacher from each of the public schools within that district providing TMR educational services.

(2) A stratified random sampling technique (based upon regional population estimates) was employed for this group to insure a balanced regional representation.

(3) The sample drawn from this group represents the most serious limitation of the survey. The appropriate state office issued a request to its seven regional offices asking them to provide the names of persons meeting the aforementioned criteria. Only three of the seven regions responded, with a total of 9 persons identified. Time restrictions did not permit a follow-up effort to determine or increase the degree of representation.

Table 3

Data on the Selection of Respondents Representing the Expert Population

Disability Category	Nominators	Number of Individuals Nominated	Number of Individuals Participating
Mentally Retarded	Thomas Higley (OARC) David Kullowatz (OARC) Walter Fuhrer (M-CARC)	26	26*
Cerebral Palsied	Richard Mathewson (UCP) Richard Mitchell (UCP)	20	20*
Epileptic	James Watson (ELO) Betty Stokes (ELO)	23	23*

*Original contacts and agreements to participate were, in part, handled by the nominators.

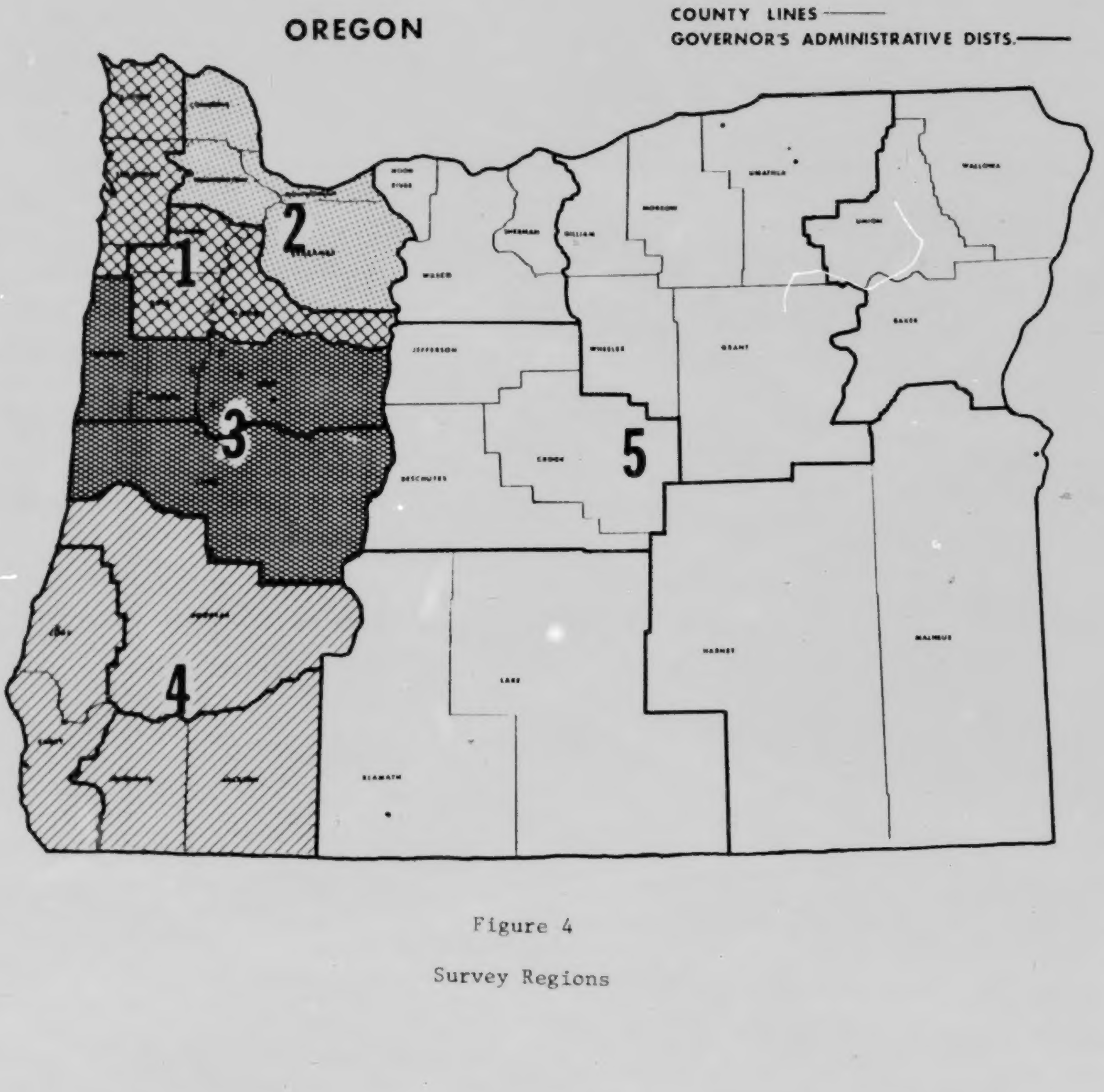

OREGON
COUNTY LINES
GOVERNOR'S ADMINISTRATIVE DISTS.
1
2
3
4
5
HOOD RIVER
WASCO
SHERMAN
GILLIAM
MORROW
UMATILLA
UNION
WALLOWA
JEFFERSON
WHEELER
GRANT
BAKER
CROOK
DESCHUTES
HARNEY
MALHEUR
LAKE
KLAMATH

Figure 4

Survey Regions

Table 4

Practitioner Representation in the Five Survey Regions

	Practitioner Groups								
Survey Regions	Vocational Rehabilitation	Work Activity Centers	Mental Health Clinics	TMR Educational Services	Special Education	Public Welfare	Child Development Clinics	Children Services	Total Repres
Region 1 (state regions 1, 3)	7	9	5	5	9	8	8	3	
Region 2 (state region 2)	5	5	10	7	20	8	9	3	
Region 3 (state regions 4, 5)	5	2	3	13	8	3			
Region 4 (state regions 6-8)	4	4	8	8	8	18			
Region 5 (state regions 9-14)	2	6	7	15	8	16		3	
Total Group Representation	23	26	33	48	53	53	17	9	

Table 4

Practitioner Representation in the Five Survey Regions

	Practitioner Groups								
	Vocational Rehabilitation	Work Activity Centers	Mental Health Clinics	TMR Educational Services	Special Education	Public Welfare	Child Development Clinics	Children Services	Total Regional Representation
1, 3)	7	9	5	5	9	8	8	3	54
2)	5	5	10	7	20	8	9	3	67
4, 5)	5	2	3	13	8	3			34
6-8)	4	4	8	8	8	18			50
9-14)	2	6	7	15	8	16		3	57
	23	26	33	48	53	53	17	9	262

A modified Delphi procedure was used to conduct the survey. The procedures were divided into three phases of activity and required four months to complete. The salient steps within each phase of the survey can be summarized as follows:

> Phase I: Generation of problem statements. The initial questionnaire introduced the survey and asked participants to generate two or three problem-statements that answered the following question: "What do you consider to be the most important problems faced either by developmentally disabled individuals you know personally or by most of the developmentally disabled in your particular region of the state?" This was the specific question for practitioners; experts were asked to answer the question in terms of their own particular disability group -- (mentally retarded, cerebral palsied, or epileptic). All respondents were instructed to use the same format as that employed during the regional workshops: a referent or topic, an assertion of "what is" with respect to that referent and a comparable assertion of "what is preferred" with respect to that referent. Respondents were given ten days to return the questionnaire and were then sent a reminder notice if they had not yet replied. A total of 210 practitioner and 58 expert replies were received by the Phase I completion date, an 80% and an 85% return, respectively.
>
> Phase II: Rating of "expanded problem-statements." Of the more than 800 problem-statements received, many either duplicated or related closely to others. By clustering them thematically, editing them, and writing extended assertions of "what is" and "what is preferred," the 800 initially generated problem-statements were reduced to 34 expanded problem-statements. These were returned to respondents for rating in terms of importance to developmentally disabled people (or, if an expert, to one of the specific categories of disabled individuals) within the respondent's own region. A 0-7 rating scale was employed: 0 indicating "no problem;" 1 indicating a problem, but one that is "relatively unimportant;" and 7 indicating an "extremely important problem." A total of 214 practitioners and 55 experts responded to this second questionnaire, an 82% and an 81% return, respectively.
>
> Phase III: Rank-ordering the expanded problem-statements. The practitioner ratings from Phase II were analyzed by combining the responses from the respondents within each of the five survey regions and the fourteen highest-rated problems within each five regions were identified; similarly, the expert ratings were analyzed separately for each of the three respondent groups and the 23 highest-rated problems within each three groups were identified. The eight resulting lists of

highest rated problems were then sent back to their respective groups. Practitioners were asked to select the seven statements most important to developmentally disabled people within their particular regions; the experts, speaking for their respective disability groups, were asked to select the twelve most important problems in the entire state of Oregon. The frequency-of-selection table for each problem was then used to rank-order all problems within each group. A total of 221 practitioner and 56 expert replies were received, an 85% and an 82% return, respectively.

Eight different lists of most critical problems resulted from the survey: one for each of the five geographic regions identified for purposes of the survey; and one for each of the three major disability groups. (Appendix B presents the highest priority problems identified on each of the final eight lists.)

The April Workshop of Oregon's State Council

In April 1973, a second workshop for Oregon's State Council was conducted, this time to identify the Council's goals and priorities for inclusion in its 1974 State Plan. Unlike their simulated experience in September, the state council now had significant input from three regional committees, a group of practitioners, and a group of experts to guide them as they attempted to define or refine state goals. (Appendix B summarizes these inputs to the state council.)

The workshop began, therefore, with presentations of the data collected during the previous six months. Council members were then asked to identify high priority goal referents and to prepare expanded goal statements for each referent, using the statements generated by the survey and regional workshops as points of departure. When the new, state-oriented statements of need had been reviewed by the full council and clarified as necessary, council members were finally asked to rank-order the full set of statements. (See Part Two, Section Four for a description of specific procedures that parallel closely those actually employed by Oregon's State Council in April 1973.) The final ranking of the Oregon Council's top eleven referents was as follows:

Table 5

The Most Important Needs of the Developmentally Disabled in Oregon as Identified and Prioritized by the State Developmental Disabilities Council in April, 1973

Rank	Need Referent*
1	Coordination of services
2	Personal rights of the developmentally disabled
3	Services for pre-school developmentally disabled
4	Identification and diagnosis
5	Funds for services
6-7	Alternative living arrangements
6-7	Counseling and training services for developmentally disabled families
8	Services for post-school developmentally disabled
9	Job training and job opportunities
10	Training for the developmentally disabled with respect to basic living skills
11	General education programs

*For the complete statements of need prepared by council members, see Appendix B.

Preparing Materials Relevant to Assessing Needs, Defining Goals, and Setting Priorities

A set of materials, refined from those developed and tested during the project year and completed during May and June of 1973, include: (1) suggested small group procedures that will enable local committees and state councils to share their perceptions of the most important needs of developmentally disabled people in their respective communities and states; and (2) instruments and suggested procedures that can be used to survey the needs of developmentally disabled people as perceived by experts or by those who actually serve them. Sections Two, Three and Four of Part II of this report comprise these materials.

Monitoring On-Going Programs and Projects

The ultimate reason for articulating a set of goals and priorities is to enable council members to evaluate the overall effectiveness of statewide operating programs for developmentally disabled people. In order to accomplish an evaluation, however, the data generated by operating programs must be in a form that permits comparison with established goals and priorities. One hope of this project, therefore, was to assist the council in designing specific data formats for monitoring the outcomes of operating programs within the state.

This proved, however, to be too large a task. Meetings with various state agency representatives revealed that several different data collection formats were already being investigated for adoption within Oregon. Given this situation, the staff decided that it could be most effective by helping coordinate and facilitate efforts to explore these various formats.

During the year, the staff worked closely with Dr. Richard Eyman, Chief of Research at Pacific State Hospital in Pomona, California, and developer of a comprehensive client-centered data system for tracking services to developmentally disabled clients. The staff also worked with Dr. Robert Schwarz, project director of a fixed point of referral center in Eugene, Oregon, in his attempt to develop and implement a different data system.

The Oregon Mental Health Division has decided to implement Dr. Eyman's data system. The fixed point of referral system is still undergoing refinement and, like the Eyman system, is not yet operable in Oregon. The state DD council is following developments in the area of data systems closely and regards the implementation of one as an important goal for next year.

Management and Program Evaluation

In the context of the present evaluation strategy, the primary responsibility of the developmental disabilities council is to manage information. More specifically, the council is chiefly responsible for examining the correspondence between the needs identified through goal setting activities and the outcomes produced by the state's operating programs. One important goal of this project, therefore, was to develop and field-test a training exercise to assist developmental disabilities councils understand and implement these managerial (evaluation) responsibilities.

The state council began to implement its evaluation responsibilities through a training exercise which offered a simulation of the evaluation process. The exercise, which was part of the April workshop, incorporated the following specific purposes: (1) to develop an understanding among participants of the need for adequate data in order to achieve meaningful evaluation of goal attainment; (2) to provide participants with a set of procedures that could be used for deciding what data are needed to assess goal achievement; and (3) to provide a reality-based experience in implementing these procedures with respect to some high priority goals of the Oregon Council.

The evaluation procedures developed for this exercise were based upon both the SPECS version of a PPBS model and our previous experiences in working with the Oregon State Council and local DD committees. Three tasks were identified, each dealing with a goal that was both relevant to the Oregon Council and illustrated one or more aspects of the evaluation process. As council members participated in the exercise, they were required to consider the following questions:

1. Are some formats more functional than others for specifying goals and evaluating their achievement?
2. What data were available on the designative state of each simulation goal at the time of its adoption?
3. What data are currently available on the designative state of each goal?
4. If the council were to ask tomorrow for evidence of goal achievement, what could be said?
5. Given available data, how could the present goals be updated for potential adoption as a high priority goal for next year?
6. Assume for a moment that the updated goals are adopted as high priority for next year. What specific kinds and sources of data would be needed in order to evaluate achievement?

In thinking through the answers to these questions in the context of a set of simulation exercises, the members of the Oregon Council became more aware of the procedures involved in accomplishing the task of evaluation.

Feedback obtained from the April workshop and from project staff was used to refine the simulation exercise materials and to prepare them for dissemination. This activity took place during May and June of 1973, and the product is presented in Part II, Section Five of this report.

SUMMARY, DISCUSSION, AND FUTURE ACTIVITIES

Summary of Progress

Between July, 1972 and July, 1973, the Oregon Developmental Disabilities Council and the Research and Training Center in Mental Retardation at the University of Oregon have collaborated on a project designed to develop a planning and evaluation strategy for monitoring developmental disabilities programs on a statewide basis. The project was funded by a Federal grant to the Research and Training Center with the expectation that the strategy being developed might be usable throughout the country.

The overall strategy involves three interrelated components: planning, influencing, and evaluating. During the project year, all three of these components were addressed, and training materials were developed to assist council members in understanding their role in implementing the strategy. Progress was made by the Oregon Council in utilizing the strategy primarily with respect to the first of the components; i.e., planning. This progress has occurred in both the State Council and within three newly established local developmental disabilities committees.

The three local committees, located in Regions 2, 5, and 10 of Oregon, came into existence through the mechanism of two-day workshops. During the workshops, each committee determined its regional priorities for the developmentally disabled for the coming year. After the workshops, the committees remained intact in order to attempt to implement their programs of priorities. Although some of their efforts have already met with success, the shortage of staff support has impeded the progress of which they are capable.

The State Council, at a meeting in April 1973 established eleven goals and priorities for the 1974 State Plan. The opinions of consumers and practitioners throughout the state were made available to Council members in order to assist them in the planning process.

At this point in time, the project's most significant progress has been made with respect to the planning portion of the strategy. Evaluation of the State Plan has not yet been accomplished. This could be accomplished, however, with one additional year of effort. In addition, the cyclical mechanism of the planning and evaluation strategy could become more firmly established.

The second year of this project, therefore, will focus primarily upon three interrelated activities: (1) further development and support of regional developmental disabilities committees in Oregon; (2) full evaluation of the Oregon 1974 State Plan; and (3) establishing goals and priorities for the Oregon 1975 State Plan.

Project Activities for the Second Year

The following work plan outlines the major activities to be accomplished over a 12 month period beginning July 1, 1973 and ending June 30, 1974.

I. Regional Committees
   A. Provide one day per month of consultation or assistance to each of the three existing regional committees.
   B. Assist in the development of five additional regional committees.
   C. Conduct two-day goal setting workshops for each of the five new committees, using procedures that were developed last year by the Federal project.
   D. Provide one day per month of consultation or assistance to each of the new regional committees as they are developed.

II. Evaluation of 1974 State Plan
   A. During July and August, 1973, collect baseline data relating to each of the eleven priorities contained in the 1974 State Plan. Provide Council with a baseline evaluation report no later than September 15, 1973.
   B. During September, 1973, distribute baseline evaluation reports to any persons or agencies that might be influenced to attend more closely to any or all of the eleven priorities.
   C. Between October, 1973 and January, 1974, establish and work with whatever task forces may be needed to improve data collection mechanisms for a follow-up evaluation to be conducted on each of the eleven priorities.
   D. During February and March, 1974, collect data for follow-up evaluation on each of the eleven priorities. Provide Council with follow-up evaluation report no later than April 15, 1974. This report will be incorporated into the 1975 State Plan.
   E. Between April 15, 1974 and June 15, 1974, collect baseline data relating to any new priorities that may be identified in the 1975 State Plan. Provide Council with baseline evaluation report no later than June 30, 1974.

III. Goals and Priorities for the 1975 State Plan
   A. Develop procedures enabling the three existing regional committees to update their goals and priorities for the 1975 State Plan. Present description of these procedures to the State Council's steering committee by November, 1973.
   B. Develop procedures enabling the State Council to update its goals and priorities for the 1975 State Plan. Present description of these procedures to the State Council's steering committee by January 1, 1974.
   C. During January and February, 1974, implement procedures for updating goals and priorities of the three existing regional committees.
   D. During March and April, 1974, implement procedures for updating the State Council's goals and priorities to be included in the 1975 State Plan.

The accomplishment of this work plan will involve a collaborative effort between the Oregon Developmental Disabilities Council and the Research and Training Center in Mental Retardation at the University of Oregon. In addition to providing assistance to the Oregon Council in completing implementation of the evaluation strategy, the experience acquired during the second project year should permit the completion of training materials that could be used by other developmental disabilities councils.

PART II

Instructional Materials

SCRIPT OF A SLIDE-TAPE PRESENTATION ILLUSTRATING A PLANNING AND EVALUATION STRATEGY FOR STATE DEVELOPMENTAL DISABILITIES COUNCILS

The planning and evaluation strategy that has been developed in this project for use by developmental disabilities councils is derived from a modification of a planning, programming, and budgeting system (PPBS). The modified model applies to organizations in which management has only limited power -- where management coordinates programs with needs, but without having absolute authority over what actually occurs in these programs. Management can only indirectly influence operating programs, by providing hard data on the discrepancies between what is needed and what existing programs actually provide.

There seems to be a high degree of theoretical congruence between this modification of PPBS and the organizational structure of state developmental disabilities councils. Because of this congruence, an operational strategy has been devised which details the activities required of a state developmental disabilities council in order to implement the PPBS model. A slide-tape presentation of this strategy has also been developed which can be used to introduce council members to their planning and evaluation responsibilities.

The following pages reproduce the script of this slide-tape presentation. Each numbered phrase, statement, or set of statements is accompanied by a slide illustration. The slide-tape kit can be ordered from the project director on a cost basis.

Script From the Presentation

1. On October 30, 1970, President Nixon signed the Developmental Disabilities Services and Facilities Construction Act...

2. ... a piece of federal legislation designed to help states expand significantly their programs for those handicapped by mental retardation, cerebral palsy, epilepsy, and other neurological conditions.

3. In order to qualify for assistance under this new Act, a state today must assume considerably more responsibility than in the past for planning, influencing, and evaluating its many on-going programs for the developmentally disabled.

4. More specifically, the Act requires that each state establish an adequately staffed state planning and advisory council...

5. ... which will offer local communities a greater voice in determining needs, establishing priorities, and delivering services...

6. ... which will continually evaluate the extent to which existing services meet those needs...

7. ... and which will submit an annual, comprehensive State Plan for allocating resources in terms of clearly defined State priorities.

8. In the remainder of this presentation, we will describe one particular strategy that can be used by a state advisory council to meet these requirements of the Developmental Disabilities Act in a systematic and comprehensive fashion.

9. To begin, planning, influencing, and evaluating -- as they are carried out by a state advisory council for the developmentally disabled -- can be most usefully thought of as sequential activities.

10. Planning involves identifying needs and then establishing goals and priorities addressed to those needs.

11. Influencing occurs prior to and during the implementation of specific programs designed to achieve those goals and priorities.

12. And evaluating requires, first, that the actual outcomes of programs be measured and, second, that those outcomes then be compared with the original goals and priorities.

13. Often, evaluative information leads to new planning, and so the cycle begins once again.

14. Crucial to all three activities -- planning, influencing, and evaluating -- is the collection and use of information.

15. In a real sense, therefore, the major task of a state advisory council is to collect and use information in such a way that the needs of the developmentally disabled throughout the state can be accurately assessed and met.

16. But let's now examine in some detail each of these three major activities -- planning, influencing, and evaluating -- and try to identify the specific kinds, sources, and uses of information they require.

17. As a state advisory council begins to plan -- that is, to identify needs and establish goals and priorities -- it can make its job considerably easier if it has four kinds of information:

18. First, information on the prevalence of developmentally disabled individuals in the state can be very helpful.

19. One way of collecting prevalence data is to conduct a house-to-house search of some statistically representative sample of the state's population.

20. An alternative approach is to apply special formulae based upon past house-to-house surveys to a state's most recent census data.

21. The latter approach is certainly far less expensive than conducting house-to-house surveys, but it usually results in less accurate information about prevalence, for it depends upon the generalizability of earlier surveys to basic census data in different communities.

22. The second kind of information that a state advisory council needs in order to plan well is an inventory of both existing and proposed services for the developmentally disabled clients of agencies and facilities throughout the state.

23. Once again, a survey can be used to obtain the desired information -- this time a survey of relevant agencies to identify both the services they currently provide to the developmentally disabled as well as those they intend to provide in the future.

24. A second way of investigating proposed services would be to analyze the existing state plans of public agencies, such as those developed by the division of vocational rehabilitation, the state department of special education, and the state department of mental retardation.

25. As an alternative to the periodic survey for examining existing services, a computerized, interagency data bank can be developed in such a way that services can be monitored as they are being provided by agencies to individual clients. This is the most accurate and ultimately desirable method for gathering this kind of information.

26. On the other hand, however, developing and operating a computerized data bank is an expensive venture. Moreover, it is frequently more politically sensitive than conducting a periodic survey, for many agencies are either unwilling or legally prohibited from sharing information about individual clients.

27. The third kind of information that a state advisory council needs to have in order to plan well is an awareness of the most important needs of the developmentally disabled in its state. In order to ascertain these needs accurately, it is important to tap the opinions of both the developmentally disabled themselves as well as those who provide them with services.

28. Telephone or mail surveys, while highly impersonal in their approach, represent one technique for reaching large numbers of

consumers and providers of services in a relatively short period of time.

29. On the other hand, small group processes can be designed to help local or regional committees of consumers and practitioners identify their own special needs, goals, and priorities.

30. In the accompanying materials, you will find a fairly detailed description of one set of mail survey techniques that can be used by a state advisory council to obtain at the "grass roots" level an answer to the question, "What do you consider to be the most critical needs of developmentally disabled citizens in your community?"

31. In addition, you will find a description of a specific set of small group processes that can be used by a local or regional committee to identify what its members consider to be the most critical needs of developmentally disabled citizens in its particular region of the state.

32. There is yet a fourth kind of information that can prove useful to a state's advisory council as it begins to engage in planning: namely, summaries of both existing and pending court decisions and legislation that are directly relevant to the developmentally disabled. These can usually be abstracted from regularly published state and federal documents.

33. Gathering together these four kinds of information for planning is, of course, only part of the challenge facing a state advisory council.

34. Equally important is seeing that the information is disseminated in digestible ways to members of the council and that the information is actually used to identify state goals and priorities.

35. In another set of accompanying materials, we have described a particular set of processes that begin to utilize the four kinds of information and can be employed by a state council to set its annual goals and priorities for the developmentally disabled.

36. In accordance with the regulations of the Developmental Disabilities Act, the ultimate product of this planning activity by a state advisory council is the annual State Plan which is submitted to the Department of Health, Education, and Welfare.

37. This State Plan can be much more than a document for external reporting and accountability to the Federal Government...

38. ... for, if used effectively, it can also be a potent instrument for influencing and stimulating improved services and programs for the developmentally disabled within the state.

39. For example, the goals and priorities enunciated in the State Plan can be used by a state advisory council as its principal criteria for funding special projects with monies from the DD Act itself.

40. In addition, the State Plan can be presented to directors of state agencies with the strong suggestion that the goals and priorities identified be used by those agencies as guidelines for allocating resources to the developmentally disabled they serve.

41. The plan can be presented to a state's governor, for eventually he must review and approve all programs of all state agencies...

42. ... and to a state's legislators, for it is they who control many of the laws and resources that inhibit or facilitate services to the state's developmentally disabled citizens.

43. And finally, the State Plan can be used as an instrument to influence those who operate at the federal level -- such as legislators, funding agencies, and advisory councils.

44. In effect, despite a state council's lack of direct control over most of the dollar resources expended for the developmentally disabled...

45. ... if the council can develop a strong State Plan, one that clearly defines critical needs, the council can exert considerable influence both within and outside its state, dramatically affecting both the quantity and the quality of services provided for its developmentally disabled citizens.

46. At this stage of the presentation, we have identified planning and influencing, through the collection and use of information, as two of the most important functions that a state advisory council can perform to help its developmentally disabled citizens.

47. Over time, however, a council's ability to evaluate the extent to which identified needs are actually being met by on-going state programs will determine that council's credibility -- not only with clients and those who serve them, but also with state and federal legislators, agencies and funding sources, and even its own members.

48. Evaluation, therefore, might well be viewed as the most critical component in this process of planning, influencing and evaluating. It is certainly the most difficult and the most important challenge facing a state's advisory council.

49. But what exactly is meant by evaluation, particularly when it is identified as a major responsibility of a state advisory council?

50. One type of evaluation is that which occurs when a professionally-trained practitioner diagnoses the specific problems or needs of an individual and then prescribes certain treatments or interventions that are designed to reduce those problems or meet those needs.

51. Obviously, this kind of "individual" evaluation, while extremely important, cannot possibly be a responsibility of a state advisory council. Rather, it must remain the work of those who deal directly with the developmentally disabled and their individual problems.

52. A second type of evaluation focuses on the specific methods or procedures that an agency employs as it works with clients to achieve particular objectives.

53. When this second type of evaluation is conducted, information is regularly gathered by the agency in order to distinguish those processes that work particularly well from those that do not.

54. Often, when the agency has immediate access to this kind of evaluative information about processes, it can make useful changes in its on-going procedures and methods -- doing more of what works and less of what does not!

55. Although critical to the work of each and every agency serving the developmentally disabled, this second type of evaluation, which requires day-to-day monitoring of agency processes, seems just as inappropriate to a state advisory council as did the earlier form of individual diagnosis or evaluation.

56. The type of evaluation that does seem appropriate -- if not mandatory -- for a state advisory council to conduct is that designed to identify how well the overall goals and priorities for all developmentally disabled citizens in the state are in fact being met.

57. To put it another way, given a set of goals and priorities in its annual State Plan, an advisory council has an obligation to measure just how much progress is made during the succeeding year in meeting those goals and priorities.

58. In order to accomplish this appropriate type of evaluation, it is once again critical, as in planning and influencing, for the council to collect and manage information.

59. First of all, a state advisory council needs to have a clear and accurate description of its state-wide goals and priorities, for it is these that will be evaluated.

60. Presumably, as suggested earlier, these goals and priorities will be defined annually by the state advisory council and included in its annual State Plan.

61. Secondly, incorporated in each goal statement should be a description of the current state of affairs -- the "what is" state -- of that goal at the time of its identification.

62. Specific information about the current state of affairs is important to a council, for not only does it legitimate each goal, it also stimulates the generation of baseline data that are essential for determining later in the year whether or not progress has in fact been made toward achieving the goal.

63. Indications of progress or change require, of course, that measures be taken on at least two different occasions.

64. Thus, as soon as possible after its goals have been identified for a particular year, a state advisory council will want to collect and organize accurate information on the current state of each goal.

65. Usually, this information can be abstracted from recent reports of agencies that serve developmentally disabled clients...

66. ... or from existing, state-wide computerized data banks of information.

67. In either case -- whether abstracted from past reports or retrieved from existing data banks -- the information gathered must be highly selective and directly related to the goals that have been enunciated in the State Plan.

68. Sometimes, of course, information on the current state of a goal is simply not available.

69. When this occurs, it is necessary for the advisory council to conduct its own special survey on the state of that goal. This may involve any of a number of possible data-gathering techniques, including questionnaires, telephone conversations, and direct observations.

70. Just as it is important for a council to have information on the current state of its annual goals immediately after their identification, it is also important for the council to gather comparable information about those goals at the end of a year of influencing and monitoring agency efforts to achieve them.

71. These year-end data represent, therefore, still another kind of information that a state council must collect if it is to engage in meaningful evaluation.

72. In most instances, the same sources as those used earlier in the year can be employed to obtain these comparable, year-end data -- reports, operating data banks, and special surveys.

73. There is one additional source of year-end information that will be relevant: namely, the set of summative evaluation reports prepared for all special projects that have been funded during the prior year with monies from the Developmental Disabilities Act itself.

74. Once these year-end data regarding the status of each goal have been collected and organized, they can be arrayed against the comparable data collected immediately after the goal had been set...

75. ... and an annual evaluation report can be prepared by or for the state advisory council -- a report that indicates...

76. ... the council's originally defined goals and priorities...

77. ... the status of those goals at the beginning and end of the year just completed...

78. ... a subjective assessment, based on the data, of progress made toward the achievement of each goal...

79. ... and specific recommendations for council members to consider as they refine old goals and establish new ones for inclusion in next year's State Plan.

80. Thus, as a state advisory council moves into its second cycle of planning and attempts to modify its goals and priorities -- it has one additional piece of information that it did not have during the first cycle of planning. It now has an evaluation report on progress made toward achievement of last year's goals and priorities.

81. Furthermore, with each cycle of planning, influencing, and evaluating, the state council ought to be generating or collecting increasingly specific and accurate information on both past accomplishments and future directions.

82. In the accompanying materials, you will find some simulated examples of evaluating goals that might be adopted by a state advisory council. The materials were designed to illustrate the flow of information from planning to evaluating to replanning.

83. At first blush, it may seem that the job of collecting and managing information, at least as it has been described in this presentation, is much too complex and large for any state advisory council to handle -- that councils simply lack the resources required to engage in such extensive planning and evaluation.

84. Since councils generally consist entirely of volunteers, it is clear that they have neither the time nor energy to do the job described if they attempt to do it entirely on their own.

85. Inevitably, therefore, state advisory councils must be able to draw upon four other sources of manpower if they are to engage in this kind of comprehensive planning and evaluation...

86. ... and, simultaneously, they must limit their own activity to monitoring the total effort, interpreting highly refined data, and making critical decisions at appropriate points in the planning and evaluation cycle.

87. One of these other sources of manpower is a council's own executive or steering committee, a subset of council members who usually have the time and expertise to play a larger role in carrying out council responsibilities than do most other members.

88. A second source of manpower can be specially constituted task forces, groups of interested individuals whose mandate becomes one of collecting and managing some particular kind of information that will be used by the council in making its decisions.

89. As a third source of manpower, a council can contract with specially-equipped individuals or groups to perform specific work that would be difficult to obtain on a volunteer basis.

90. And finally, the most important source of manpower for a state advisory council is its own staff of state employees...

91. ... for, regardless of their number, it is these staff members who inevitably are responsible for implementing the many decisions made by a state council during its deliberations.

92. By way of summary, therefore, the major functions of a state advisory council for the developmentally disabled include planning, influencing, and evaluating.

93. All three of these activities require the collection and use of information.

94. The activities occur sequentially and cyclically, each cycle providing input to new cycles of planning, influencing, and evaluating.

95. Planning, which involves identifying needs and then establishing goals and priorities, is facilitated if four kinds of information are available...

96. ... prevalence statistics, descriptions of existing and proposed agency services, opinions about important needs, and reviews of significant laws and court cases.

97. The most important product of planning is each council's statement of goals and priorities for inclusion in its State Plan.

98. This statement of goals and priorities can be used to influence the Council's own funding of special projects, the activities of on-going state agencies, and decisions which affect developmentally disabled citizens that may be made by governors, legislators, and others in positions of power.

99. Finally, the statement of goals and priorities should be used to stimulate the council's own evaluative activities...

100. ... its collection of data with respect to each goal at the time it is adopted as well as one year later ... its analysis of the data collected at those two points in time ... its assessment of progress made toward accomplishment of identified goals...

101. ... and its recommendations for subsequent cycles of planning.

102. Finally, with each annual cycle of planning, influencing, and evaluating... the quality of information available to a council ought to improve...

103. ... its procedures for planning, influencing, and evaluating ought to become more precise...

104. ... and, most important, the quality of services to developmentally disabled citizens ought to improve, thereby enhancing their opportunities for enjoying a normal and satisfying life.

ONE WAY TO INVOLVE A LOCAL COMMITTEE IN DEFINING GOALS AND PRIORITIES FOR THE DEVELOPMENTALLY DISABLED

Introduction

As a representative group of consumers, practitioners, and interested citizens, the members of a local DD committee have special knowledge and insights about the most critical needs of developmentally disabled people in their community. How to tap this knowledge and insight, and then how to organize the information generated into useful statements of local goals and priorities -- these represent a real challenge for any local DD committee in the United States.

The particular procedures described below and identified as the DAP group processes represent one possible response to this challenge. They have been adopted from a generalized technique for identifying problems, one that has been employed by over one hundred groups during the past three years.[1] Three regional DD committees in Oregon employed the modified processes in 1972-73 to identify their most important goals for 1973-74.[2] Because the processes require face-to-face interaction, they can be used most effectively by a local DD committee in a workshop setting, one that involves three major clusters of activity: approximately one-half day for committee members to generate and clarify initial statements of need; a second half-day for the workshop's trainers to collate the initial statements and develop expanded statements of need; and a final half-day for committee members to review the expanded statements, identify those that will be goals, and then assign priorities to them.

---

[1] The generalized DAP processes for joint problem-solving were developed and pilot-tested by F. Lee Brissey and John M. Nagle as part of a project sponsored by the U. S. Office of Education and conducted at the Center for the Advanced Study of Educational Administration (CASEA), University of Oregon, Eugene, Oregon.

[2] Local DD committees in Regions 2, 5, and 10 of Oregon pilot-tested these modified DAP processes as part of a larger project sponsored by the Rehabilitation Services Administration and carried out between June 1972 and June 1973 by the Rehabilitation Research and Training Center at the University of Oregon in conjunction with the Oregon Developmental Disabilities Planning and Advisory Council.

The final products of the DAP processes are two: (1) a list of expanded statements of need that have been generated by individual committee members, checked on two occasions for group understanding, and then rated for importance by all committee members; and (2) a subset of the five to ten most critical of those expanded statements, identified as goals and rank-ordered for priority by the entire local DD committee. Presumably, these two products can be helpful both to the committee as it plans its own activities and to the State Advisory Council as that group attempts to identify the most critical goals for all developmentally disabled individuals in the state.

Although the following description focuses on one particular sequence of group activities, it will be readily apparent that variations in both the sequence and the activities not only are possible, but may be desirable. Some, but not all of these variations have been suggested at appropriate points in the description.

The Concepts Underlying the DAP Group Processes

DAP is the acronym for a generalizable set of concepts and procedures which the members of a group or organization can employ to refine their problem-solving skills and bring them to bear on "real-life," day-to-day problems -- regardless of whether they be programmatic, administrative, or interpersonal in nature. This is not to suggest that DAP -- and all that it connotes -- is a sure-fire way for groups and organizations to solve all their problems simply and without conflict; rather it is a set of ideas and techniques that we think a group or organization can employ to "smoke out" some of its most important problems or needs, "unpack" them to manageable size, and then eventually develop plans for at least coping with them, if not actually solving them. The major interest of DAP, therefore, is in finding ways for groups of individuals to reduce unnecessary and pointless conflict, misunderstanding, and frustration with respect to both their goals and the methods they will employ to achieve those goals.

Underlying DAP is a set of assumptions about human beings, problems, needs, and goals, and the phases of activity required for successful joint problem solving. These assumptions are derived from a variety of sources, principally the literature related to general systems theory and human communication:

> Assumption #1: Each human being is a fully-integrated, problem-solving system, continuously engaged in three kinds of inquiry -- designative inquiry (D) about "what is;" appraisive inquiry (A) about "what is preferred;" and prescriptive inquiry (P) about "what to do" to reduce discrepancies, whether existing

or potential, between "what is" and "what is preferred."[3] It is these discrepancies or gaps that we typically identify as "problems" or "needs."

Similarly, groups and organizations engage in the same three kinds of inquiry, each of which produces particular kind of information relevant, first, to identifying problems or needs and, then, to meeting or solving those problems or needs. Essentially, therefore, human beings and organizations are viewed in DAP as systems that continuously collect and process information relevant to problems or needs and their solution.

Assumption #2: Communication is the glue used to couple together individual problem-solving systems in the business of joint problem-solving. Moreover, five critical levels of communicative contact can be applied to any piece of designative, appraisive, or prescriptive information, and, thus, to any statement of a problem or need and to any proposal for its solution. These five levels are fidelity, understanding, acceptance, relevance, and commitment. That is, successful communication requires that one move successively from merely replicating a message, to understanding and agreeing with it, to seeing it as relevant, and eventually to behaving consistently with it.

Assumption #3: The full cycle of problem solving, whether carried out individually or jointly with others, involves three major phases of activity: (a) identification of the problem or need to be addressed; (b) development of a plan for dealing with that problem or need; and (c) implementation and assessment of the plan. Moreover, within each of the three major phases of activity, it is possible to apply each of the five levels of communicative contact. For example, identifying problems or needs of a group requires that group members process information in such a way that they can achieve successful communicative contact at each successive level, from fidelity when they initially identify problems or needs to commitment when they finally decide for which of those problems or needs they will jointly develop a plan. The full DAP joint problem-solving processes, therefore, can be nicely depicted by a grid in which the three major phases of activity are spread across the top and the five levels of communicative contact are listed down the side.

---

[3] C. S. Morris, in his text Significance and Signification, discusses in considerable detail these three kinds of inquiry and the implications for information resulting from each.

For a local DD committee, the critical question to be addressed is, "How can the members of the committee pool their individual perceptions and come to consensus on the most critical needs of the developmentally disabled in their community?" Therefore, for purposes here, a local DD committee is interested in only the first of the three phases of activity in the total DAP process. The remainder of this section presents, first, a general description of the workshop activities proposed for a local committee and, then, a set of detailed notes for a workshop trainer.

An Overview of the DAP Processes for Identifying Local Needs of the Developmentally Disabled

Presumably common to the members of a local DD committee is their concern for developmentally disabled people in their particular community. What may not be common among committee members, however, is their knowledge or perception of the most critical needs or problems facing those developmentally disabled individuals. The DAP processes, as they are proposed here, are designed to help committee members share information and eventually come to consensus on the top priority goals of developmentally disabled people in their community. The focus, therefore, is on identifying needs or goals rather than on developing solutions; the process moves gradually from many voices to one voice; and the ultimate product is a set of high priority goals for a year of local committee activity.

During most of the first half-day session of the workshop, the local committee operates in relatively small groups of five or six members each. Within each small group, initial statements of need are generated by individuals and then refined to the point that they are understandable not only to members of each small group, but to members of other groups as well. These statements of need are addressed to the question, "What do you consider to be the most important problems or needs faced either by developmentally disabled individuals you know personally or by most developmentally disabled individuals in your particular region of the state?" While the question orients committee members primarily to problems or needs of the developmentally disabled, it certainly does not preclude problems or needs of individuals or agencies who provide services to the developmentally disabled. Ultimately, of course, both points of view are important, but the principal orientation of a local DD committee probably ought to be to the consumers of services rather than to their providers.

Instead of responding to relatively unstructured request for "needs" or "goals," each small group is asked to generate statements that have a definite structure, consisting of (1) a referent or topic, (2) a designative assertion of *what is* with respect to that referent, and (3) a comparable assertion of *what is preferred* with respect to that referent. Here, for example, are two illustrative statements of need, "rda's" as they come to be identified by a group.

(r) referent	(d) designative assertion of "what is"	(a) appraisive assertion of "what is preferred"
1. Opportunities for volunteers	There is not an adequate program in our region for volunteers who want to help or who are concerned about the developmentally disabled.	I prefer that there be a number of programs or opportunities for volunteers who want to work with and help the DD.
2. Prevalence	We do not have accurate data on the number and location of developmentally disabled individuals in our region.	I prefer to know exactly how many and where developmentally disabled individuals reside in our region.

During an initial brainstorming session, members of each group generate a set of rda's based on their individual perceptions of need. These are recorded and publicly displayed as they are generated. Following the brainstorming session, each group returns to its list and processes each rda for maximum clarity and understanding, not only among members of its group, but hopefully among those outside the group as well. Given the constraints of a half-day session and a general dearth of designative information about developmentally disabled people in most communities, it is most unrealistic to expect that each small group will produce rda's that have undeniable clarity and specificity. It should be possible, however, to reduce much of the ambiguity that tends to characterize the initial statements generated and to develop, at the very least, a shared understanding within each small group of the needs that have been described. The final activity of the first half-day calls for each group to make a second pass through its list of clarified rda's, this time in an effort to use whatever information is currently available to weed out gross untruths in each rda's designative assertion.

Between the two half-day sessions for committee members, the workshop trainer collates, organizes, clusters, and refines the rda's into a single list of "expanded" statements of need. To the extent possible, he combines related designative and appraisive assertions -- using some to exemplify and others as headings for entire clusters of problems or needs. He maintains, however, the rda format. Moreover, he views this collation task as purely a semantic one; that is, while he may edit and reorganize the original statements of need, the workshop trainer has no prerogative to add or delete content to any of the designative or appraisive assertions.

During the second half-day session, the expanded and reworked rda's are presented to the full local DD committee. As each expanded statement is presented, committee members monitor it for distortion of the original rda's and revise it as necessary to assure maximum understanding and acceptance by all members of the committee. When as much clarity and accuracy have been achieved as time will permit, committee members discuss the relative importance of each statement of need and then assign a measure of priority to it.

As indicated earlier, the final products of this modified form of the DAP processes are two: (1) a list of expanded statements of need that have been generated by individual committee members, checked on two occasions for group understanding, and then rated for importance by all committee members; and (2) a subset of the five to ten most critical of those expanded statements of need, identified as goals and rank-ordered in priority by the entire committee.

Notes to a Workshop Trainer

Some Pre-Workshop Considerations

1. Just as a State Advisory Council for the developmentally disabled ought to be a representative group of consumers, practitioners, and interested citizens, so too a local DD committee ought to represent a balance of these same three points of view. Therefore, prior to identifying needs and setting priorities, you may want to suggest to the existing local DD committee that it reassess its membership and make whatever changes are necessary to assure representativeness.

2. Because the DAP processes rely primarily on input from small groups of five or six members each, the total committee need not be limited to a particular size. Ideally, it ought to number between 20 and 30 members, but the DAP processes have been used quite successfully with groups as large as 100. Although the data increase significantly as the committee increases in size, and the collation task multiplies in complexity, the basic concepts and operations remain essentially the same regardless of the size of the total group.

3. Before the workshop begins, acquaint yourself fully with all of the steps in the DAP process for identifying goals and priorities. Your responsibility as a workshop trainer will be to coordinate both people and information -- requiring, therefore, that you understand fully the processes in which the committee will be involved.

4. During the course of the workshop, you will need several different kinds of materials and equipment. These include an overhead projector; clear acetates for overhead projection; acetate pens (preferably indelible); any acetates that have been prepared in advance for explaining points to the committee; enough large sheets of butcher paper for each small group to use as it generates and processes its rda's; a dozen or so felt-tip pens; and 200-300 index cards. How these various materials will be used is described below.

5. Finally, you must decide (1) how much theory underlying the DAP processes you want to present to members of the local committee and (2) how detailed a description of workshop activities you want to give during your introductory comments. Attention to each of these can range from little or no comment to extensive discussion. Your decision is not an easy one, for in virtually every local DD committee you will find some individuals who only want to know how to work the DAP processes, while others will be unhappy if you do not first describe the conceptual framework underlying those processes. Satisfying completely both kinds of individuals is obviously impossible. Therefore, let your special knowledge of the committee, your personal proclivities, and your past experiences as a workshop trainer and participant be your guide as you decide both how much and how to tell the committee about the DAP concepts and its procedures, both during your introductory comments and prior to each workshop activity.

The First Half-day of the Workshop

1. Begin with introductory comments regarding:

    a. the objectives of the workshop, including...

        1. its focus on problems or needs of the developmentally disabled within your community rather than across the state;

        2. the desire to formulate and assign priorities to these statements of local need in such a way that they can (1) give direction to subsequent committee activities and (2) influence the State Advisory Council for the developmentally disabled as it goes about its own job of identifying and assigning priorities to state-wide needs; and

        3. the workshop's focus on problems or needs faced by the the developmentally disabled themselves, but without

excluding concerns of those who provide services to the developmentally disabled.

b. the conception underlying the DAP group processes, including...

   1. distinctions among designative, appraisive, and prescriptive inquiry and information (see the brief exercise on distinguishing among the three kinds of statements at the end of this section);

   2. the notions of what constitutes a "need" or "problem;"

   3. the five levels of communicative contact; and

   4. the three major phases of activity in the total DAP process for individual and organizational problem solving.

c. and the specific workshop activities proposed for the committee, including...

   1. the procedures that will be employed to move from individual statements of need to a group product of goals and priorities;

   2. the specific format for generating and recording statements of need (see Example 1 at the end of this section); and

   3. one example from a prior workshop illustrating how information generated by individuals will be processed during the workshop to form a group product (see Example 2 at the end of this section).

2. Organize the total committee into small groups of five or six members each, and describe the following task:

   "In each small group, address yourselves as individuals to the following question:

   'What do I consider to be the most important problems or needs faced either by developmentally disabled individuals I know personally or by most developmentally disabled in this particular region of the state?'

   Organized into small groups so that you can stimulate one another, brainstorm answers to this question. Ask one of your members to serve as a recorder and, as each statement of need is identified by individual group members, make certain that the statement is recorded on the butcher paper for all group members to see -- first a referent, then a designative assertion about "what is" with respect to that referent, and finally a comparable appraisive assertion about "what is preferred" with respect to that referent. The role of each group's recorder, in addition to contributing items himself, is to record, but not to edit. The role of all group members is to generate as many rda's as possible in 30-45 minutes without stopping to clarify or argue over the truth, or value of any of the items generated by any group member. At this point, therefore, simply produce items -- that's the charge for each small group."

And as each group sets to work on that charge, rotate among the groups, interrupting only when a group appears to have forgotten its charge.

3. When the brainstorming session appears to have spent itself, review with the entire committee the next step in the process -- searching for clarity on the initial statements of need. Then ask each small group to return to its brainstormed list, discuss each of the rda's on that list, and, as necessary, clarify statements by providing examples and/or editing referents, designative assertions, and appraisive assertions. The challenge here is to clarify the rda's by paraphrasing and discussion, but to do so without distorting the meaning intended by the individuals who originally generated them. Discussion and editing, therefore, should be for the purpose of clarifying meaning -- both within the group and, if possible, for others not in the group -- rather than for the purpose of achieving agreement on either the truth of designative assertions or the desirability of appraisive assertions.

   Depending upon time constraints, suggest that group members begin by individually rating each statement for clarity, and then devote the remainder of their time to those statements most in need of clarification; or else suggest that they simply budget an arbitrary period of time to discuss each statement. Again, the focus at this point in the process should be solely upon a search for understanding or clarity, leading as appropriate either to revision of existing statements or addition of new ones.

4. As the next step, ask group members to take another look at the clarified statements of need, this time to weed out gross inaccuracies in each rda's designative assertions. The aim

here is to achieve the greatest accuracy and agreement possible, but to do so within the inevitable constraints of available time and information. No group should expect to press any of the designative assertions to its ultimate truth. Furthermore, little effort should be made here to reach consensus on the preferences expressed in each appraisive assertion. If one member disagrees substantially with a preferential statement, simply suggest that a new statement of need be written, processed, and added to the list rather than allow the group to discuss indefinitely their differences of opinion.

5. When all of the statements of need have been processed for clarity and for as much accuracy as possible, ask group members to copy the resulting rda's on index cards, one card for each, including a referent and its comparable statements of what is and what is preferred. When the cards have been completed by each group, adjourn the session and invite the committee to reconvene for its second half-day session at an appointed time.

Between Sessions

Between the two half-day sessions, your job is (1) to cluster thematically each of the individual statements of need now recorded on index cards and (2) to write for each cluster an "expanded" statement of need. (Once again, see Example 2 at the end of this section.) In effect, your job is to combine related individual statements of need, using some to exemplify and others to serve as general statements for an entire cluster. The rda format should again be used, so that each expanded statement has a referent and short paragraphs of comparable and thematically related designative and appraisive assertions about that referent. Because these will be shared with committee members during the second half-day session, the entire list of expanded rda's should be reproduced in multiple copies; at the very least, the items should be prepared for presentation by means of an overhead projector, one expanded rda per acetate. Our experience has been that the final set of expanded statements of need will number between 25 and 35.

The Second Half-day of the Workshop

1. During the second half-day of the workshop, present the expanded rda's to the full committee and then test each statement for clarity, truth, and distortion. The search for clarity and truth is parallel to that conducted earlier in small groups; the test for distortion is a check on your interpretation of the multiple items that have been organized into single expanded statements of need. It is probably

desirable to present all expanded rda's first and then to process each for clarity, truth, and possible distortion. (Form 1 at the end of this section may facilitate this refining process.) As each set of statements is processed, revise it as necessary to maximize understanding or clarity and minimize distortions or inaccuracies. Moreover, provide ample opportunity for committee members to add additional statements of need if they feel that none of the expanded rda's adequately reflects one or more of their original statements of need. Be extremely reluctant, however, to remove any of the statements, unless all members of the committee agree to do so. Throughout the DAP processes, preserving each individual voice is far more critical than pruning the list of minority viewpoints.

2. When each expanded rda has been adequately processed for clarity, accuracy, and lack of distortion, move to the next step in the process -- rating by each committee member of the importance of each statement. Give the full committee the following directions:

> "As I once again display each of the expanded statements of need -- statements that have been processed for clarity, accuracy, and lack of distortion -- consider it carefully in light of this question:
>
> > 'How important on a 1-7 scale, where 1 indicates low importance and 7 indicates high importance, do I think it is to the developmentally disabled in our community that the need described in this particular statement be met -- that is, that the identified discrepancy between what is and what is preferred be reduced?'
>
> If you still do not understand any of the expanded statements of need, or if you disagree with either its designative or appraisive assertions, or if you think that it so badly distorts the original rda's that you cannot possibly rate it for importance, then rate the statement 0."

Next present each expanded rda, giving committee members adequate time to rate it for importance. (Form 2 at the end of this section may facilitate this rating task.) Collate the ratings, and then compute and display their frequencies for each expanded statement. It is, of course, possible to collate the ratings orally and therefore publicly, but it is probably preferable to do so privately so that individual opinions and biases can be protected. Moreover, in computing frequencies, you may want to group the 0's, 1 and 2's, 3, 4, and 5's, and 6 and 7's rather than treat them independently. In effect, if you do this, you will be reducing eight categories to four for the purposes of collating.

3. As an optional next step, when the frequency data have been displayed, allow members of the committee to argue briefly for placing more or less importance on particular expanded statements of need -- particularly those for which the data suggest considerable disagreement regarding either the existence of the need or its importance. If you do allow for this period of argument, allow as well for re-rating each of the expanded rda's for which arguments have been presented.

4. Whether or not the prior optional step is taken, the frequency scores for each expanded rda result in one of the workshop's two products: a list of expanded statements of need that have been generated by individual committee members, checked on two occasions for group understanding, and then rated for importance by all committee members.

5. There are several ways to produce the second workshop product: the subset of five to ten most critical goals, rank-ordered in priority by the entire committee. One technique is simply to give each expanded statement a "total score" based on its previous importance scores. These "total scores" can then be arranged from highest to lowest, in effect rank-ordering the expanded statements of need from most to least important.

   An alternative procedure, although slightly more complex, separates the initial rating of importance from the rank-ordering for priority. Given the display of frequency scores for all of the expanded rda's, isolate as a subset the ten rda's that have high ratings of importance (6 or 7 on the seven-point scale) and low spread (most of the responses clustered near the upper end of the scale). Allow for argument within the full committee on the relative priority of each of these ten expanded rda's. Then ask each committee member to select from the subset the five rda's that he thinks deserve highest local priority. When these individual selections have been collated, a frequency-of-selection score can be computed for each rda and used to rank-order all of the rda's in the subset.[1]

6. When the two products have been completed, you may want to ask committee members to indicate their personal commitment to them. Again, a seven-point scale can be used and the results collated and publicly displayed. This time, the essential question becomes, "On a seven-point scale, how committed are you to the two lists of statements of need -- as guidelines for future activities of

---

[1] The committee may want to cluster its most important items into two or three groups rather than rank order them; or it may simply want to identify, without distinguishing among them, its "top five" or "top seven" goals.

the local committee and as information to be forwarded to the State Advisory Council for the developmentally disabled?" (Form 3 at the end of this section may facilitate this final rating for commitment.)

7. Finally, produce for the local DD committee copies of their two products -- the total list of expanded rda's with their ratings of importance, and the subset of highest priority rda's rank-ordered in terms of importance. In preparing these final products, you may want to preface them with a brief description of the membership of the local DD committee and the specific processes employed to define these goals and priorities.

Exercise 1

Distinguishing Among Three Kinds of Statements: Designative, Appraisive, and Prescriptive

Let's try to distinguish among three kinds of statements, each of which conveys a different kind of information:

1. a designative statement conveys information about "what is" with respect to oneself, his environment, or his relationship to that environment. Presumably, therefore, it is a statement of fact. Moreover, it represents "public events," and so the "territory" mapped by the statement is fully open to the independent inspection of other observers and to their independent judgment regarding the degree to which the statement accurately maps that territory. Given a designative statement, the question of "truth" is extremely relevant.

2. an appraisive statement conveys information about "what is desired" with respect to oneself, his environment, or his relationship to that environment. It is, therefore, not a statement of fact, but a statement of preference or value. That is, unlike a designative statement, an appraisive statement represents "private events" and so it cannot be publicly verified except by inference. Arguing the "truth" of an appraisive statement is, thus, quite different from arguing the "truth" of a designative statement.

3. a prescriptive statement designates actions to be taken or behaviors to be exhibited in order to achieve a particular end. It is, therefore, a statement of proposed action. It represents forms of action that can be taken to change either the characteristics of the environment or one's relationship to that environment.

Based on these definitions, use a "d" for designative statements, an "a" for appraisive statements, and a "p" for prescriptive statements to identify whether each of the following statements is more designative, more appraisive, or more prescriptive.

____ 1. There is currently no diagnostic clinic or research center for the developmentally disabled in the town of ____.

____ 2. Job opportunities for trained DD are very scarce.

____ 3. I wish that all doctors and nurses be specially trained to deal with the specific problems of the DD.

____ 4. Publish a monthly newsletter for DD in the region that describes services that are available to them and ongoing activities in which they may want to become involved.

____ 5. I would like to see detailed information about who the DD actually are and where they currently live.

____ 6. Most treatment for the DD in this region requires that they travel outside its boundaries.

____ 7. Buy a new fleet of buses that can provide more reliable transportation for the DD.

____ 8. I prefer to be informed about the school's classification of my DD child following its diagnosis and grouping.

____ 9. There are no educational programs for the trainable mentally retarded in our region's public schools.

____10. Coordinate a series of sheltered workshops for DD during the early summer months.

Example 1

Formatting Statements of Need: A Referent and Comparable Designative and Appraisive Statements

We'd like to use a particular format for specifying needs of the developmentally disabled, one that builds on distinctions between designative and appraisive statements. Each need will have three component parts: (1) a referent, a label for the general topic or thing we're talking about; (2) a designative statement regarding that referent; and (3) an appraisive statement regarding that referent. The resulting need can then be defined as the "d-a discrepancy" between "what is" and "what is preferred" with respect to the referent.

For example, given "my car" as a referent, here are two of the many possible statements of need that could be developed with respect to that referent:

	Referent	Designative Statement	Appraisive Statement
1.	my car	Whenever it rains, my car leaks something terrible, and my feet get soaking wet.	I prefer that my car leak not one drop when it rains.
2.	my car	It is the cheapest and smallest model Ford makes.	I prefer it to be the most deluxe Cadillac a man could buy.

In each example, there is a discrepancy between "what is" and "what is preferred" with respect to "my car."

When developing statements of need that have this format, try to avoid collapsing designative and appraisive statements -- that is, avoid veiling values in designative statements. For instance, look at the following example:

Referent	Designative Statement	Appraisive Statement
the coffee pot	There is too little attention to the coffee pot in the morning.	There should be more attention to the coffee pot in the morning.

At first glance, the designative statement in the above example appears to be a legitimate statement of fact; upon closer inspection, however, note that the statement implies far more about "what is preferred" than it says about "what is."

Avoid as well confusing prescriptions or solutions with either statements of fact or statements of preference. Look, for instance, at this example:

Referent	Designative Statement	Appraisive Statement
the coffee pot	It is empty until 10:00 in the morning.	The janitor should fill it when he arrives.

In this example, the appraisive statement is actually a prescription -- a proposed action -- rather than a statement of preference. As a result, it is difficult to identify the particular need being described -- that is, the specific discrepancy between "what is" and "what is preferred."

A more useful statement of need would read:

Referent	Designative Statement	Appraisive Statement
the coffee pot	The pot is empty until 10:00 in the morning.	I usually want a cup of coffee when I arrive at 8:00 in the morning.

Example 2

The following example illustrates how statements of need (rda's) from four small groups were combined into a single expanded rda. Changes that occurred as a result of checks for clarity, truth, and distortion are also illustrated.

1. Five statements of need from four small groups, as originally brainstormed and as revised:

   Group 1, Item 14.

   Original statement:
   Referent: Special living arrangements for DD
   Designative Assertion: Limited local services (group homes, foster homes, etc.) to place DD's in lieu of institutions.
   Appraisive Assertion: Get DD out of institutions where appropriate.

   Clarified statement:
   Referent: Alternative living arrangements for DD
   Designative Assertion: Limited local facilities (group homes, foster homes, etc.) to place DD's in lieu of institutions.
   Appraisive Assertion: Get DD out of institutions where appropriate and into appropriate living arrangements.

   Group 2, Item 4.

   Original statement:
   Referent: Some DD's
   Designative Assertion: Residence not available near services (both permanent and temporary).
   Appraisive Assertion: Prefer residences near services.

   Clarified statement:
   Referent: Some DD's
   Designative Assertion: Protective living environments not available near services (both permanent and temporary).
   Appraisive Assertion: Prefer permanent living environment near services.

Group 2, Item 5.

Original statement:
Referent: Severely retarded
Designative Assertion: No residential services in Lane County.
Appraisive Assertion: Prefer residential services in Lane County.

Clarified statement: No changes were made on this statement.

Group 3, Item 3.

Original statement:
Referent: Adult moderately and mild retarded population
Designative Assertion: Lack of living facilities.
Appraisive Assertion: Adequate group supervised living facilities.

Clarified statement:
Referent: Adult moderately and mildly retarded population
Designative Assertion: Lack of living facilities to promote independent living.
Appraisive Assertion: Should be adequate supervised living facilities.

Group 4, Item 3.

Original statement:
Referent: Housing for disabled
Designative Assertion: Adult lack of suitable housing and supportive services to live independently.
Appraisive Assertion: Prefer housing and services be available.

Clarified statement:
Referent: Housing for disabled
Designative Assertion: Adult handicapped lack of suitable housing and supportive services on all levels of community living.
Appraisive Assertion: Prefer housing and services be available.

II. The expanded statement of need based upon the five rda's received from the four small groups:

Referent: Alternative living arrangements for the DD

Designative Assertion: In Lane County, there are limited alternative living arrangements -- few group homes, foster homes, community homes, etc. -- that will promote independent living.

Appraisive Assertion: I prefer that there be more residential services and more suitable housing for the DD in Lane County... that there be more protective living arrangements, both permanent and temporary, near available services ... that there be more group supervised living facilities ... that, to the extent possible, the DD be able to live outside formal institutions.

III. The expanded statement of need revised by the entire committee:

Referent: Alternative living arrangements for the DD

Designative Assertion: In Lane County, there are limited alternative living arrangements -- few group homes, foster homes, community homes, etc. -- that will promote independent living and/or total care, particularly for the severely disabled.

Appraisive Assertion: I prefer that there be more residential services and more suitable housing for the DD in Lane County... that there be more protective living arrangements, both permanent and temporary, near available services... that there be more group supervised living facilities... that to the extent possible, the DD be able to live outside of formal institutions.

Form 1

To "weed out" unnecessary ambiguity, distortion, or factual error in the expanded statements of need, please respond to each question for each item.

	How do you rate this expanded rda for understanding? (1-low, 7-high)	Do you think this expanded rda significantly distorts one or more of the original statements? (Yes or No)	Do you have good reason to doubt the truth of any or all of the designative assertions in this expanded rda? (Yes or No)
1	1 2 3 4 5 6 7		
2	1 2 3 4 5 6 7		
3	1 2 3 4 5 6 7		
4	1 2 3 4 5 6 7		
5	1 2 3 4 5 6 7		
6	1 2 3 4 5 6 7		
7	1 2 3 4 5 6 7		
8	1 2 3 4 5 6 7		
9	1 2 3 4 5 6 7		
10	1 2 3 4 5 6 7		
11	1 2 3 4 5 6 7		
12	1 2 3 4 5 6 7		
13	1 2 3 4 5 6 7		
14	1 2 3 4 5 6 7		
15	1 2 3 4 5 6 7		
16	1 2 3 4 5 6 7		
17	1 2 3 4 5 6 7		
18	1 2 3 4 5 6 7		
19	1 2 3 4 5 6 7		
20	1 2 3 4 5 6 7		

Form 2

Individual Tally Sheet for Rating Importance of the Expanded Statements of Need

For each expanded rda, ask yourself the following question:

> "How important on a 1-7 scale (1 low, 7 high) is it to the developmentally disabled in this region that the particular need be met -- that is, that the particular discrepancy between 'what is' and 'what is preferred' be reduced?"

If you still don't understand the statement of need or don't think it really represents a need, and you therefore can't rate it for importance, simply rate it 0.

Circle your rating for each rda:

Item	Rating	Item	Rating	Item	Rating
1.	0 1 2 3 4 5 6 7	21.	0 1 2 3 4 5 6 7	41.	0 1 2 3 4 5 6 7
2.	0 1 2 3 4 5 6 7	22.	0 1 2 3 4 5 6 7	42.	0 1 2 3 4 5 6 7
3.	0 1 2 3 4 5 6 7	23.	0 1 2 3 4 5 6 7	43.	0 1 2 3 4 5 6 7
4.	0 1 2 3 4 5 6 7	24.	0 1 2 3 4 5 6 7	44.	0 1 2 3 4 5 6 7
5.	0 1 2 3 4 5 6 7	25.	0 1 2 3 4 5 6 7	45.	0 1 2 3 4 5 6 7
6.	0 1 2 3 4 5 6 7	26.	0 1 2 3 4 5 6 7	46.	0 1 2 3 4 5 6 7
7.	0 1 2 3 4 5 6 7	27.	0 1 2 3 4 5 6 7	47.	0 1 2 3 4 5 6 7
8.	0 1 2 3 4 5 6 7	28.	0 1 2 3 4 5 6 7	48.	0 1 2 3 4 5 6 7
9.	0 1 2 3 4 5 6 7	29.	0 1 2 3 4 5 6 7	49.	0 1 2 3 4 5 6 7
10.	0 1 2 3 4 5 6 7	30.	0 1 2 3 4 5 6 7	50.	0 1 2 3 4 5 6 7
11.	0 1 2 3 4 5 6 7	31.	0 1 2 3 4 5 6 7	51.	0 1 2 3 4 5 6 7
12.	0 1 2 3 4 5 6 7	32.	0 1 2 3 4 5 6 7	52.	0 1 2 3 4 5 6 7
13.	0 1 2 3 4 5 6 7	33.	0 1 2 3 4 5 6 7	53.	0 1 2 3 4 5 6 7
14.	0 1 2 3 4 5 6 7	34.	0 1 2 3 4 5 6 7	54.	0 1 2 3 4 5 6 7
15.	0 1 2 3 4 5 6 7	35.	0 1 2 3 4 5 6 7	55.	0 1 2 3 4 5 6 7
16.	0 1 2 3 4 5 6 7	36.	0 1 2 3 4 5 6 7	56.	0 1 2 3 4 5 6 7
17.	0 1 2 3 4 5 6 7	37.	0 1 2 3 4 5 6 7	57.	0 1 2 3 4 5 6 7
18.	0 1 2 3 4 5 6 7	38.	0 1 2 3 4 5 6 7	58.	0 1 2 3 4 5 6 7
19.	0 1 2 3 4 5 6 7	39.	0 1 2 3 4 5 6 7	59.	0 1 2 3 4 5 6 7
20.	0 1 2 3 4 5 6 7	40.	0 1 2 3 4 5 6 7	60.	0 1 2 3 4 5 6 7

Form 3

Satisfaction/Commitment Response Form

After approximately one full day of effort, you have produced two group products: (1) a list of expanded statements of need that were originally generated by individuals, checked on two occasions for group understanding, and rated by the total group for importance; and (2) a subset of statements that, after having been rated by most participants as extremely important, have been subsequently prioritized by the entire group.

We would like to raise two final questions:

1. On a 1-7 scale (1 low, 7 high), how committed are you to the first of these two products, the total list of expanded statements of need, each with its frequency of importance ratings? Are you willing to have the list used as an input for future decision-making at the regional and state levels?

   0 1 2 3 4 5 6 7

2. On a 1-7 scale (1 low, 7 high), how committed are you to the second of these two products, the subset of high priority statements of need, rank-ordered from most to least important? Are you willing to have this rank-ordering or priorities used as an input for future decision-making at the regional and state levels?

   0 1 2 3 4 5 6 7

A DESCRIPTION OF SURVEY PROCEDURES FOR IDENTIFYING STATEWIDE AND/OR LOCAL NEEDS OF THE DEVELOPMENTAL DISABLED

Introduction

The survey procedure outlined in this section offers an alternative to the small group procedures previously described for providing State DD Councils with information regarding the statewide and/or local needs of developmentally disabled people. The procedure developed from the realization that while there are knowledgeable and experienced persons capable of speaking for the needs of developmentally disabled people in their respective regions of the state, it can be tremendously difficult to bring such persons together or to otherwise organize their perceptions in any useful and efficient manner.

The procedure employed was inspired by the Delphi technique. Originally developed at the RAND Corporation, the Delphi technique is a means of soliciting and collecting the opinions of experts. Its initial uses were primarily in the area of technological forecasting, but more recently it has been used as a technique for identifying agreement concerning organizational problems, goals, and objectives. The most important characteristics of the Delphi approach are: (1) the anonymity of the survey participants; (2) a numerical analysis of the participants' responses; and (3) the use of controlled opinion feedback to participants in a series of successive questionnaires.

Since participants in a mail survey are unknown to one another, the technique also prevents persons of influence from unduly overriding or swaying the opinions of other participants. Communication between participants is maintained by summarizing the responses to one round of questions and providing this information to participants with the next round of questions.

The present set of procedures includes the development and dissemination of three sequential questionnaires dispersed over a period of approximately three to four months. Four major phases of activity are required. Phases one, two, and three each culminate in the preparation and mailing of the three questionnaires. Phase four involves the analysis of data from the third questionnaire and preparation of a final report for the State Council.

The questionnaires are designed to solicit opinion regarding respondents' perceptions of the more important needs of developmentally disabled people in their community or throughout the state. Two final products result from this survey procedure. The first is a listing of all needs identified and rated for importance. From this list, the needs receiving the highest ratings are selected to be rank-ordered for priority. The rank-ordered list of needs constitutes the second product of the survey.

These survey procedures have been implemented to assist the Oregon Developmental Disabilities Council in its identification and prioritization of statewide needs of developmentally disabled citizens. The DAP framework for conceptualizing needs, described in the previous section for implementation in small groups, was also utilized in this survey procedure in order to ensure comparability of results with those produced by the small groups.

The remainder of this section will detail specific procedures for implementing the four phase survey, based on our experiences in the state of Oregon. Variations of these procedures will undoubtedly be required in response to each unique situation where such a study might be conducted. The end of this section includes the survey instruments that were used in the Oregon study.

Implementation of the Needs-Assessment Survey

Phase 1

Step 1: Establish a steering committee. The function of a steering committee is to serve as an advisory panel of experts at particular junctures in the survey process. The committee should include knowledgeable representatives from both "provider" and "consumer" groups and also at least one person with expertise in survey methodology. In addition, it is strongly recommended that several key members of the Council also serve on the steering committee. The Council's participation in basic planning and implementation decisions will help to ensure their acceptance of the final survey products.

Step 2: Identify the major question(s) needing resolution. The steering committee should provide advice on the proposed question to be put to the respondents.

Example: What do you consider to be the most important problems faced either by developmentally

disabled individuals you know
personally or by most develop-
mentally disabled in your
particular region of the state?

Particular care should be taken in finalizing the specific wording of the question. For example, words that are vague, ambiguous, or unnecessarily long or technical should be replaced. As a final check, ask several uninvolved colleagues to test the clarity of the statement.

Step 3: Identify the relevant population of respondents. Here again, the steering committee should assist in developing a list of possible respondents or respondent groups from which the sample is to be selected. The choice of the respondent population will, of course, depend on the specific survey objectives. The choice will also depend to some extent on the resources available to conduct the survey. The final selection, however, will undoubtedly include respondents from the following three categories: (1) "providers" of services or practitioners; (2) "consumers" of services or clients (where appropriate, this category can be broadened to include the parents of the developmentally disabled); and (3) nominated "experts" who are well acquainted with the problems of developmentally disabled persons.

Step 4: Select the respondents. After determining the total sample size that is feasible for a given study, selection of respondents from the "provider" category will usually involve consideration of the following criteria: (1) necessary respondent qualifications, such as years of experience in providing a service, or percentage of DD clients in the professional caseload; and (2) relevant agencies from which respondents will be selected. It should be possible to determine which agencies serve the greatest number or provide the broadest range of statewide services to developmentally disabled individuals.

Somewhat different criteria are recommended for selecting respondents from the "expert" category. These criteria are guided by two general assumptions: first, there are persons highly knowledgeable about the problems of the developmentally disabled; and second, these knowledgeable persons or "experts" can be identified on the basis of their reputations.

After identifying individuals to serve as nominators of the expert respondents, it may be helpful to employ a set of "selection guidelines" by which all potential respondents can be compared. For example:

(a) all persons nominated more than once are to be considered as possible respondents;

(b) a person nominated more than once with at least two strong recommendations is to be selected;

(c) a person nominated only once but with strong recommendation is to be selected in preference to a person nominated more than once but with no strong supporting recommendation; and

(d) no person is to be selected who has not received at least one nomination with a strong recommendation.

When selecting respondents from the consumer or client category, it is best either to sample from the parents of clients, or to employ the nomination technique to identify clients capable of accomplishing the required task. The names and addresses of clients or client representatives may be considerably more difficult to obtain than the names of providers or experts, since rather strict regulations usually govern access to this kind of information. One possibility is to enlist the assistance of the public or private agencies where such records are kept; they may be willing to make the initial contact with the clients and to provide you with the required information once client agreement to participate is obtained.

Step 5: Obtain the respondents' cooperation. The respondents selected for participation in the study should be individually contacted by telephone to enlist their support. Before making the contacts, however, it is suggested that a telephone message be prepared and used with all respondents. The message should explain: (a) the purpose and importance of the study; (b) the methodology to be employed; (c) how respondents were selected; and (d) what will be required of those who agree to participate. After obtaining the respondents' verbal commitment to the project, one additional step is recommended. A letter of confirmation should be forwarded to respondents specifying in greater detail the purpose of the study and the approximate amount of time involved. An enclosed postcard to be returned to the researcher can provide confirmation of the respondents' correct name, address, and telephone number along with a written commitment to the project.

Step 6: Prepare and mail the first questionnaire. The purpose of the first questionnaire is to obtain the respondents' answers to the major research question being posed for resolution. Since all other questionnaires will build upon the data received from this questionnaire, clarity concerning the task to be performed is extremely important. The questionnaire used in the Oregon study can be found at the end of this section.

It is wise to decide upon the amount of time participants will have to return their responses. Our experience has indicated that a response-time interval of 10-12 days is desirable, especially where the study involves a large number of respondents, and where a high response rate is expected. Be sure to enclose a pre-addressed stamped envelope for the return of the response forms with all questionnaires; this courtesy is considered a must to guarantee even minimal returns. Soon after mailing the first questionnaire, a "reminder notice" can be sent to all respondents who have not returned their replies by (or perhaps a few days before) the deadline date.

Phase 2

Step 1: Analyze the replies obtained from questionnaire #1. The primary purpose of this step is to organize and, to some extent, summarize the responses that will be resubmitted to participants for additional consideration. This procedure should involve some variation of the following general steps. (1) Make a copy of each returned statement on a separate 3 X 5 index card. (2) Sort the cards into piles of thematically related statements. It is wise to have a colleague work with you to check the accuracy of your clustering or sorting results. (3) Eliminate obvious duplications in each cluster, and (4) combine closely related items. When these two steps are completed, each cluster should be composed of unique but thematically related statements. (5) If appropriate, rewrite some of the items for greater clarity and/or conciseness. (6) As a final step, following the rda formats, collapse and rewrite the individual statements to form one "expanded" statement of need. (An illustration of the clustering procedures involved in deriving an expanded statement of need can be found toward the end of this section.)

Step 2: Prepare and mail the second questionnaire. The second questionnaire is designed to allow participants to make a judgment concerning the importance of the needs that were identified in the first questionnaire. This task can be accomplished by instructing the participants to rate each expanded statement of need on a scale of importance. The questionnaire used for this purpose in the Oregon study can be found at the end of this section.

Phase 3

Step 1: Analyze the replies obtained for questionnaire #2. The ratings from the second questionnaire should be compiled and recorded on a master tally sheet. Separate data analyses should be performed for each of the several regions or groups involved in the survey.

Step 2: Prepare and mail the third questionnaire. The task for the third questionnaire requires participants to reconsider a list of top-rated needs and to make one final judgment indicating priorities. A decision must first be made concerning the number of top-rated need statements to include in this third questionnaire. Participants should then be asked to select or choose approximately half of the need statements from the total list. A copy of the third questionnaire in the Oregon study can be found at the end of this section.

Phase 4

Step 1: Analyze the replies obtained from questionnaire #3. Rank-ordering of the need statements can be accomplished by tallying the frequency with which they were selected. Separate analyses can be conducted for each of the subgroups in the survey.

Step 2: Present the final results to the steering committee. The steering committee should examine the results and make recommendations concerning any additional steps in the data analysis that might be conducted. They may also want to discuss the most effective way of preparing the final report for presentation to the Council.

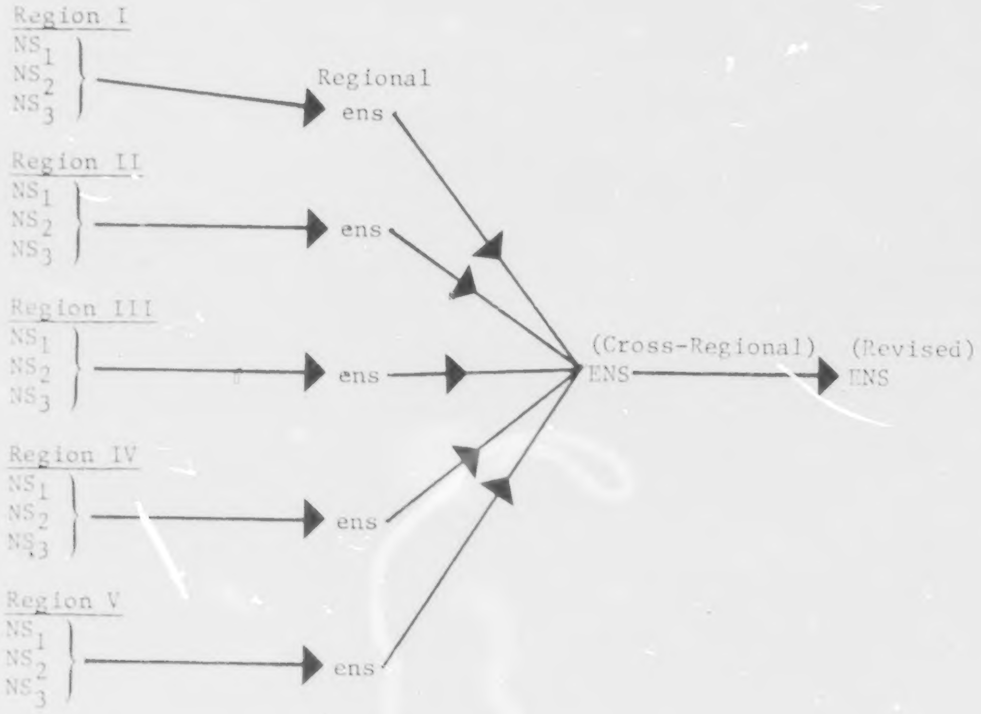
Step 3: Prepare and submit report to the State Council.

Step 4: Prepare and mail report to participants.

An Illustration of the Expanded Problem-Statement Clustering Process

The following diagram illustrates the clustering process involved in deriving an "expanded" statement of need.

Figure 1


Region I
NS1
NS2
NS3
Regional
ens
Region II
NS1
NS2
NS3
ens
Region III
NS1
NS2
NS3
ens
Region IV
NS1
NS2
NS3
ens
Region V
NS1
NS2
NS3
ens
(Cross-Regional)
ENS
(Revised)
ENS

As shown in the figure, need statements generated by participants in each of the five regions are thematically clustered to form a regional expanded need statement. Similar expanded need statements from each of the regions are then combined and rewritten to form one expanded need statement that is cross-regional in content. Finally, this draft of the cross-regional expanded need statement is revised to refine its clarity and representativeness.

To further illustrate this important procedure, we are including the following example of the clustering process involved in deriving an expanded need statement based upon the DAP problem generating format. Tables 1 through 4 are, in effect, illustrations of the diagram presented above. Table 1 presents individual "d-a" need statements that were generated by four of the five regions in the Oregon study concerning the central theme of "Transportation Needs of the Developmentally Disabled." Table 2 lists the expanded need statements resulting from the clustering of individual need statements within each region. Table 3 presents the expanded need statement derived by combining the four regional expanded need statements. Table 4 presents the final revised form of the cross-regional expanded need statement.

Table 1

Individual Need Statements for Each Regional Group

Region I:

1. D - Some clients walk, some clients wait for rides, and some clients are brought by parents or relatives.
   A - I would prefer a bus that would pick up and take back clients at a specific time.
2. D - Public transportation is non-existent in our community.
   A - A daily bus service throughout the county for transportation to jobs, medical services, and social living activities including spectator sports.
3. D - Community transportation is not oriented toward DD persons.
   A - Specialized transportation services and devices should be readily available.
4. D - Transportation is not provided for the students.
   A - I would prefer that transportation be provided.

Region II:

1. D - Since the developmentally disabled tend to be widely scattered in a rural district, transportation is scarce, expensive or almost impossible.
   A - Transportation should be made available to the disabled at a reasonable rate and at reasonable times.
2. D - Students in special education classes seem to have great difficulty in arranging their own transportation. They rely heavily on parents and/or teachers to cart them around.
   A - Individualized attention within schools to assess student transportation needs.
3. D - There is a problem of lack of adequate transportation -- the severely disabled find it difficult to use buses -- when available.
   A - Special transportation facilities to take these people places for social contact.
4. D - A mentally retarded client living in a rural area was denied training due to a lack of personal and/or public transportation.
   A - I prefer that transportation be made available to all developmentally disabled individuals who have been accepted for training.

Region III:

1. D - Transportation for the non-ambulatory developmentally disabled is virtually nil, especially for ancillary services such as recreation programs and religious education.

Table 1 (continued)

A - Vans equipped with hydraulic lifts are needed in all population centers.

Region V:

1. D - Insufficient transportation for the developmentally disabled.
   A - Varied public transportation to meet the needs of the developmentally disabled.

Table 2

Regional Expanded Need Statements Derived by Combining and Rewriting the Individual Statements from each Regional Group

---

Region I:

What is: There is no adequate public transportation in this community for DD persons. Agencies must budget for private carriers or depend on volunteers.

What is preferred: The community should provide a variety of services to transport the disabled to schools, jobs, medical facilities, and recreation centers.

Region II:

What is: There is a lack of adequate transportation for the DD. Most importantly, transportation to and from service agencies and job sites is extremely limited. Special education students, for example, must often rely on parents and teachers for their transportation needs. The accommodations that do exist are rarely equipped to handle the special needs of the severely disabled population. Accommodations in rural areas, where the DD tend to be widely scattered, are particularly scarce and are often too expensive for many to use.

What is preferred: I prefer that transportation accommodations be available to all the DD who need it. . .that it be available at reasonable rates and at convenient times, especially for those families isolated in rural areas . . .and that special accommodations be provided for transporting the severely disabled.

Region III:

What is: There is virtually no transportation for the non-ambulatory disabled, especially to allow them to participate in support programs, such as recreation.

What is preferred: Specially equipped vehicles should be provided by communities to transport their disabled citizens to and from various activities.

Region V:

What is: There is insufficient transportation to meet the needs of the DD in our community.

What is preferred: A variety of public transportation should be made available.

Table 3

Cross-regional Expanded Need Statement

What is: There is a lack of adequate transportation to meet the needs of the DD in our community. Most importantly, transportation to and from service agencies, schools, job sites, and social and recreational facilities is extremely limited. Moreover, the carriers that do exist are not adequately equipped to accommodate the severely handicapped and non-ambulatory client. In rural areas, where the DD tend to be widely scattered, transportation is even more scarce and often too expensive. Many agencies must either budget for private carriers or depend on volunteers for providing transportation.

What is preferred: I prefer that a variety of transportation alternatives be made available for all the DD in our community who require such facilities, regardless of the severity of their disability or their ability to pay. These services should be available at convenient times, particularly for clients residing in rural or out-of-the-way areas.

Table 4

Final Revised Expanded Need Statement

What is: There is inadequate transportation for the DD to and from service agencies, schools, job sites, and social and recreational facilities. Moreover, existing carriers are not adequately equipped to accommodate DD who are severely handicapped and nonambulatory. Rural areas, where the DD tend to be widely scattered, have even fewer and more expensive transportation alternatives than other areas. Many agencies must either budget for private carriers or depend on volunteers.

What is preferred: I prefer that a variety of transportation alternatives be available at convenient times to all DD, regardless of the severity of their handicap, their ability to pay, or their place of residence.

The remainder of this section includes copies of the questionnaires that were used in the Oregon study.

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

MODIFIED DELPHI INVESTIGATION: NEEDS IDENTIFICATION

This is Part One of the modified Delphi Investigation in which you have kindly agreed to participate. Even before we begin, therefore, let us extend our sincere thanks to you for agreeing to take the time and effort to contribute to our final product.

The topic of the investigation is "Developing State Priorities for the Developmentally Disabled in Oregon." (The Developmentally Disabled are defined, at this time, as the mentally retarded, cerebral palsied, and/or epileptic.)

The researcher is Mr. Kenneth Fox of the Rehabilitation Research and Training Center in Mental Retardation, University of Oregon. The supervisor of this study and director of the Research and Training Center is Dr. Andrew Halpern.

Purpose

This investigation has been designed by the Rehabilitation Research and Training Center in Mental Retardation, University of Oregon, for use by the state of Oregon's Developmental Disabilities (DD) Advisory Council. The information collected in this investigation will be provided to the DD Advisory Council to aid Council members in their attempt to assess the immediate/future needs of the developmentally disabled throughout the state.

The investigation seeks to identify the major problems currently facing the developmentally disabled in Oregon so that wherever possible, programs can be developed or other appropriate actions taken to deal with these problems.

Participant Information

As a member of a professional group concerned with providing services to the developmentally disabled, you are, we believe, uniquely qualified to help us in this process. It is our task to draw on your knowledge and opinions, and to provide the communication vehicle for you to share your perceptions with us and with other professionals serving the developmentally disabled.

The research technique being used in this investigation is one which requires a series of brief contacts by mail. On subsequent contacts we will be providing you with summary information concerning the products and perceptions of your entire group. We feel sure that the generation of this kind of information will be of great value to us and, we hope, a rewarding experience for you.

Before we move on to the specific task for Phase One, however, perhaps it would be helpful to briefly focus on the importance of the investigation, and to indicate how the generated information will be used, by providing some background information on the function of the DD Advisory Council.

Background Information

The DD Advisory Council is the sole official body responsible for the planning and coordinating of services for the developmentally disabled on a statewide basis. The Council is composed of a representative group of clients, practitioners, and interested citizens whose primary responsibility is for annual review and approval of a state plan concerned exclusively with the developmentally disabled. This responsibility requires that the Council be able to evaluate the extent to which existing services meet the needs of the developmentally disabled, and from an examination of the discrepancies between needs and services, to develop a list of priorities for the allocation of resources.

The Council's mandate with respect to evaluation is far reaching and complex. The accomplishment of this overall task requires a series of intermediate steps, the most urgent of which is the direct concern of this investigation -- to somehow ascertain the needs of the developmentally disabled from both regional and statewide perspectives.

Focus

The problems that this study seeks to identify are major problems currently faced by the developmentally disabled. In other words, we would like to focus primarily on the problems of the client-consumer. However, don't hesitate to suggest problems faced by those who provide services to the developmentally disabled when you feel that these are of prime importance to the client.

Problem Format

Finally, we would like to generate your Phase One problem-statements using a particular format. Experience has indicated that this particular type of problem-statement format is relatively easy to work with, and produces statements which not only convey much more information, but are also more easily understood by others.

Each problem-statement should consist of two separate components: (1) an assertion as to "*what is*" with respect to some general subject matter, and (2) an assertion of "*what is preferred*" with respect to that same subject matter. Stated differently, the "*what is*" component describes the current state of affairs of the problem situation. It should be an assertion of *fact* (as opposed to a statement of value) and should therefore indicate a state of affairs which could be checked by other observers. The "*what is preferred*" component tells us how you would prefer that state of affairs to be. It is not a statement of fact, but a statement of *preference* or *value*. Unlike the "what is" statement, the "what is preferred" statement cannot be publicly verified as to its truth.

One or two examples may help to clarify the distinction between the two components:

"What Is"	*"What Is Preferred"*
I have time to read one book a month.	I would prefer to read at least four books a month.

Notice in the above example that both statements have a common focus or referent -- the number of books I have time to read in a period of one month. Notice also that an attempt was made to be as precise as possible. Instead of using phrases like "not enough time," or "too few books" (phrases which mean different things to different people), reference was made to the exact time period and number of books involved in my problem.

"What Is"	*"What Is Preferred"*
At my office the first pot of coffee is seldom ready until 9:00 in the morning.	I prefer that the coffee be ready when I arrive at 8:10 in the morning.

This example involves my problem of not being able to get coffee early in the morning. Again, an attempt was made to be as precise as possible in specifying the current and the preferred state of affairs.

ID No. ___

One last caution. Try to avoid confusing prescriptions or solutions with either statements of facts or statements of value. Look, for instance, at this rewording of the last example:

"What Is"	*"What Is Preferred"*
At my office the first pot of coffee is seldom ready until 9:00 in the morning.	The janitor should make coffee when he arrives.

In this example the "what is preferred" statement is actually a prescription -- a proposed action -- rather than a statement of preference. As a result, it is difficult to identify the particular problem being described.

The Task

> *You are asked to reflect on the information presented above and then to generate two or three problem-statements in answer to the following question? "What do you consider to be the most important problems faced either by developmentally disabled individuals you know personally or by most developmentally disabled in your particular region of the state?"*

Please concentrate on major problems, but also attempt to be as precise as possible. If you believe your problem-statement applies to one particular disability group (for example the epileptic) or to one particular age group (for example the pre-school), please state these qualifiers as part of your problem-statement.

All communications received are strictly confidential. You are asked to fill out the attached personal data sheet and to include your name on each returned form for statistical and operational purposes ONLY.

Deadline

Since there are subsequent stages in this investigation, and in order that all problems received may be processed for the second stage, you are asked to return the attached personal data and problem-statement sheets in the stamped addressed envelope provided by December 9, 1972. We suggest that you retain this introductory information for your future reference.

If you have any questions concerning the study, please do not hesitate to contact me at the Research and Training Center, University of Oregon. My telephone number at the university is 503 - 686 - 5466 and at home, 503 - 343 - 4639.

Your cooperation is sincerely appreciated.

KENNETH D. FOX

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

PROBLEM - STATEMENTS

NAME: ______________________________

Note: *The information above the dotted line will be removed upon receipt of this form.*

ID # ______________________________

STATEMENT OF THE TASK: *"What do you consider to be the most important problems faced either by developmentally disabled individuals you know personally or by most developmentally disabled in your particular region of the state?"*

(1a) *"What Is"*

(1b) *"What Is Preferred"*

(2a) *"What Is"*

(2b) *"What Is Preferred"*

(3a) *"What Is"*

(3b) *"What Is Preferred"*

PLEASE RETURN IN THE ENVELOPE PROVIDED ALONG WITH THE ATTACHED DATA SHEET. THANK YOU.

CONFIDENTIAL INFORMATION

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

MODIFIED DELPHI INVESTIGATION

(NOTE: PERSONAL DATA IS FOR STATISTICAL AND COMPUTATIONAL PURPOSES ONLY.)

NAME: ____________________

Note: *The information above the dotted line will be detached upon receipt of this form.*

- -

CURRENT OCCUPATION: ____________________ ID# ________

SEX: Male ____
Female ____

YOUR AGE RANGE:
under 21 ____ 21 - 30 ____ 31 - 40 ____
41 - 50 ____ 51 - 60 ____ 61 + ____

ARE YOU CURRENTLY PROVIDING A SERVICE DIRECTLY TO THE DEVELOPMENTALLY DISABLED:
Yes ____
No ____

PLEASE ESTIMATE THE PERCENTAGE OF YOUR PROFESSIONAL CONTACT WITH EACH OF THE FOLLOWING DISABILITY GROUPS:
(1) Mentally Retarded ___%
(2) Cerebral Palsied ___%
(3) Epileptic ___%
(4) Multiply Handicapped ___%
100%

PLEASE ESTIMATE THE PERCENTAGE OF YOUR PROFESSIONAL CONTACT WITH CLIENTS OF THE FOLLOWING AGE RANGES:
(1) 0 - 6 years ___%
(2) 7 - 18 years ___%
(3) 19 - 50 years ___%
(4) 51 + years ___%
100%

PLEASE ESTIMATE YOUR TOTAL EXPERIENCE IN WORKING WITH THE DEVELOPMENTALLY DISABLED.
Years ____

REHABILITATION RESEARCH AND TRAINING CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

MODIFIED DELPHI INVESTIGATION: NEEDS IDENTIFICATION

This is Part Two of the modified Delphi Investigation in which you have kindly agreed to participate. Once again let us extend our sincere thanks to you for agreeing to take the time and effort to contribute to our final product.

Review of General Information

As you recall, the topic of the investigation is "Developing State Priorities for the Developmentally Disabled in Oregon." (The Developmentally Disabled are defined, at this time, as the mentally retarded, cerebral palsied, and/or epileptic.)

This investigation has been designed by the Rehabilitation Research and Training Center in Mental Retardation, University of Oregon, for use by the State of Oregon's Developmental Disabilities (DD) Advisory Council. The information collected in this investigation will be provided to the DD Advisory Council to aid Council members in their attempt to assess the immediate/future needs of the developmentally disabled throughout the state.

The investigation seeks to identify the major problems currently facing the developmentally disabled in Oregon so that wherever possible, programs can be developed or other appropriate actions taken to deal with these problems.

Your Responses to Part One

In Part One of the study, you were asked to generate two or three problem statements in answer to the following question: "What do you consider to be the most important problems faced either by developmentally disabled individuals you know personally or by most developmentally disabled in your particular region of the state?" In writing your problem statements, you were asked to utilize the following guidelines.

Each problem-statement should consist of two separate components: (1) an assertion as to "what is" with respect to some general subject matter, and (2) an assertion of "what is preferred" with respect to that same subject matter. Stated differently, the "what is" component describes the current state of affairs of the problem situation. It should be an assertion of fact (as opposed to a statement of value) and should therefore indicate a state of affairs which could be checked by other observers. The "what is preferred" component tells us how you would prefer that state of affairs to be. It is not a statement of fact, but a statement of preference or value. Unlike the "what is" statement, the "what is preferred" statement cannot be publicly verified as to its truth.

In response to this request 223 persons from throughout the state produced more than 600 problem statements for us to consider. These statements have been clustered into 27 "expanded problem statements" and are now presented for your further consideration. During Part Two of the study, you will be asked to make some judgments about these expanded problem statements.

Your Task in Part Two

Although a few of you who agreed to participate in this study did not complete Part One, we are asking all of you to participate in Part Two. Your task will be to rate each of the expanded problem statements with respect to its importance within your community. Consider the following example:

> Legal Services for the DD
>
> What Is: There is currently no provision in our community for legal counseling that is geared especially to the needs of the DD.
>
> What Is Preferred: I prefer that legal counsel capable of representing the needs of the DD be available in every court in our community.

0	1	2	3	4	5	6	7
Not A Problem	Slightly Important			Moderately Important			Extremely Important

If you do not think that the above statements represent a problem in your community, then circle "0" on the scale. If you think they describe a slightly important problem, then circle "1" on the scale. At the other extreme, a rating of "7" would indicate that you regard the problem as extremely important in your community.

As you rate the 27 expanded problem statements for importance, please keep the following guidelines in mind:

1. Each item is to be rated independently. There is no limit on the number of problems you might regard as extremely important or slightly important or anywhere in between.
2. You should rate each problem in terms of its importance in your community.
3. You may not agree with everything that is contained in an expanded problem statement. If you agree with most of the statement, however, you should circle one of the importance ratings (one through seven) rather than the "reject" rating (zero).

Deadline

In order that replies may be processed for Part III of the study, please return your ratings in the envelope provided by Friday, February 9, 1973. You may retain these instructions for future reference.

Again, if there are any questions please contact Mr. Kenneth Fox at 686-3591.

Your cooperation is sincerely appreciated.

PLEASE RETAIN THESE INSTRUCTIONS FOR FUTURE REFERENCE. THANK YOU.

REHABILITATION RESEARCH AND TRAINING CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

EXPANDED PROBLEM STATEMENTS

ID # __________

Statement Of The Task: Please rate each of the following problem statements with respect to its importance to the disability group for which you are responding and within your community.

1. Public Understanding and Acceptance of the DD

What Is: The public, while often solicitous, does not generally understand the developmentally disabled or accept them as full-fledged members of the community; rather, it tends to over-emphasize their shortcomings and ignore their potential for growth. Worse, the fears and misconceptions the public harbors are manifested in extensive social prejudice against the DD, who, as its victims, suffer ridicule, humiliation, and rejection. Families, associates, and professionals who deal with the DD are by no means innocent of such prejudices.

What Is Preferred: I prefer that the public -- including parents, associates, employers, teachers and other service workers -- understand and accept the needs and abilities of the DD. State agencies, public schools, and the media might cooperate in programs to teach the public ways of helping the DD and to encourage community interaction with the DD.

0	1	2	3	4	5	6	7
Not A Problem	Slightly Important			Moderately Important			Extremely Important

2. Adequate Income For the DD

What Is: Income for the disabled, whether from employment, social security, or public assistance, is very inadequate.

What Is Preferred: Income to the disabled should be sufficient for them to enjoy life styles that are as normal as possible.

0	1	2	3	4	5	6	7
Not A Problem	Slightly Important			Moderately Important			Extremely Important

The remainder of this form has not been reproduced here in order to conserve space.

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

MODIFIED DELPHI INVESTIGATION: NEED IDENTIFICATION

FINAL STAGE

Introduction

This is the third and final stage of the modified Delphi study concerned with developing state priorities for the developmentally disabled in Oregon. Once again we wish to thank you for your time and effort spent on parts one and two of the study. Your participation has contributed very significantly to the present development of the project. We realize that a study of this nature places considerable demand on respondents, and this is another reason why your contribution is so greatly appreciated.

Summary of the Study to Date

In Part One of the study you were asked to generate statements focusing on the major problems of the developmentally disabled in your particular region of the state. These individual statements were then clustered and combined into a series of "expanded problem statements." In Part Two you were asked to rate each of the expanded problem statements with respect to their importance within your community.

The ratings from Part II were analyzed by combining your responses with the responses of other participants representing your region of the state. The list of problem statements presented in this final questionnaire, therefore, represents those problems judged by your regional group as being of greatest importance. During Part Three of the study you are asked to make one last judgment about these problem statements.

Your Task in Part Three

Your task in Part Three is to reconsider the enclosed 14 problem statements and to select from this list the seven problem statements which you believe to be of greatest importance within your community. You are asked to signify your choice by marking the appropriate spaces on the enclosed response sheet.

When making your selections do not be concerned with ranking the statements in any particular order of importance. You are simply to check those seven statements which you believe represent the most urgent problems facing the developmentally disabled within your community.

Deadline

In order that replies may be processed as quickly as possible, please return the enclosed response sheet in the envelope provided by March 9, 1973. If you have any questions concerning this final stage, please contact me at 686-3591.

In appreciation for your participation, a report summarizing the results of this study will be made available to you upon request. If you wish to receive a copy of the report, please check the appropriate space on the response sheet.

Again, thank you for your continuing cooperation.

Kenneth D. Fox

Regional Code No. I

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

EXPANDED PROBLEM STATEMENTS

Statement of the Task: Please read all of the following problem statements and, on the enclosed response sheet, select the seven statements which you feel are the most important within your community.

1. Public Understanding and Acceptance of the DD

What Is: The public, while often solicitous, does not generally understand the developmentally disabled or accept them as full-fledged members of the community; rather, it tends to over-emphasize their shortcomings and ignore their potential for growth. Worse, the fears and misconceptions the public harbors are manifested in extensive social prejudice against the DD, who, as its victims, suffer ridicule, humiliation, and rejection. Families, associates, and professionals who deal with the DD are by no means innocent of such prejudices.

What is Preferred: I prefer that the public -- including parents, associates, employers, teachers and other service workers -- understand and accept the needs and abilities of the DD. State agencies, public schools, and the media might cooperate in programs to teach the public ways of helping the DD and to encourage community interaction with the DD.

2. Adequate Income for the DD

What Is: Income for the disabled, whether from employment, social security, or public assistance, is very inadequate.

What Is Preferred: Income to the disabled should be sufficient for them to enjoy life styles that are as normal as possible.

The remainder of this form has not been reproduced here in order to conserve space.

ID No. ___ Regional Code No. I

REHABILITATION RESEARCH AND TRAINING
CENTER IN MENTAL RETARDATION

UNIVERSITY OF OREGON

PHASE THREE RESPONSE SHEET

Instructions for Completing the Response Sheet: Please indicate your selection of the seven most urgent problems in your community by placing a check in the space to the right of each selected item below.

1. Public Understanding and Acceptance of the DD ____
2. Adequate Income for the DD ____
3. Training in Living Skills for the DD ____
6. Opportunities for the Post-School-Aged DD ____
7. Treatment for the Emotionally Disturbed DD ____
9. Educational Programs for all DD ____
10. Parental Involvement and Acceptance of the DD ____
13. Job Training for the DD ____
15. Alternate Living Facilities for the DD ____
19. Job Opportunities for the DD ____
21. Coordination of Services ____
22. Special Learning Disabilities ____
26. Funding Programs for the DD ____
27. Preschool Opportunities for the DD ____

Please check the space to the right if you would like to receive a copy of the report summarizing the results of this study. ____

PLEASE DETACH AND RETURN THIS RESPONSE SHEET IN THE ENVELOPE PROVIDED. THANK YOU.

TWO ALTERNATIVE WAYS TO INVOLVE A STATE DD COUNCIL IN DEFINING STATEWIDE GOALS AND PRIORITIES FOR DEVELOPMENTALLY DISABLED CITIZENS

To qualify for federal assistance under the Developmental Disabilities Act, each state must establish an adequately staffed state planning and advisory council that can periodically evaluate existing services to developmentally disabled citizens and prepare an annual State Plan for improving both the scope and quality of these services. More specifically, the mandate requires that a state council annually define a set of goals and priorities for the succeeding year and then use these (1) as a vehicle for influencing others who provide services to the developmentally disabled, (2) as a guide for the council's own resource allocation decisions, and (3) as a basis for collecting evaluative data at the beginning and end of that particular year.

When a council engages in systematic planning for the first time, it probably has no prior set of statewide goals and priorities or, if it does, that set may be considered by council members to be essentially inadequate. Described below, therefore, are two alternative processes that we think a council can employ to define a new set of goals and priorities. One of these alternatives allows council members to generate goal statements themselves; the second alternative provides them with a base of potential goal statements from which they can select or develop their own set of goals and priorities. Finally, we have included a few brief comments regarding the processes that a council might employ to modify or refine its existing set of goals and priorities in subsequent years.

Alternative One

This first alternative set of processes calls for the state council to replicate at the state level the exact same set of small group processes described earlier for use by local DD committees. As indicated in that description, the processes require inputs from small groups of individuals -- inputs that are identified as statements of need or rda's consisting of referents or topics, assertions of what is with respect to each referent, and comparable assertions of what is preferred with respect to each referent. This time, the inputs are addressed to the general question, "What do you consider to be the most important needs of either developmentally disabled individuals you know personally or most developmentally disabled in our state?" Each small group generates its own set of statements of need and then processes those statements for interpersonal understanding and acceptance.

The rda's from all groups are then collated or clustered thematically, and expanded statements of need are prepared, presented to the total council, and checked for understanding, acceptance, and distortion. When the complete array of expanded rda's has been processed, members of the council are invited to argue for the relative importance of particular statements and then to rate and rank order in terms of importance the total array of expanded statements of need.

Other than changing the context of inquiry, therefore, from needs of the developmentally disabled in one region of the state to needs of the developmentally disabled throughout the state, the same processes for defining goals and priorities described earlier can also be used by a state council. If so, as before, the state council's final products will be two: (1) a list of goal statements or expanded statements of need, each of which was originally generated by individuals, checked on two occasions for group understanding, and then rated by the total membership of the state council for importance; and (2) the subset of goal statements that, after having been rated by most participants as extremely important, were subsequently prioritized by the entire group. Either or both of these products can be included in the council's annual State Plan; both can be used to influence others in the state; and either or both of these products, though probably only the highest priority goals, can be used as a basis for gathering evaluative data.

Alternative Two

This second alternative set of processes assumes that the state council has a list of potential goal statements generated by others in the state from which council members can select and modify the particular statements that they want to include in their own set of statewide goals and priorities.

To exemplify, assume that each of ten local DD committees in a particular state has employed the DAP group processes described earlier, and has developed a rank-ordered list of its top ten goals for the ensuing year. Because many of these 100 locally-defined goal statements will overlap in content, they can usefully be categorized by referents or topics to simplify their presentation to state council members. Suppose, for instance, that the 100 statements cluster around twenty-five reasonably distinct content areas or referents; if so, they can be most meaningfully presented to state council members if they are organized in a booklet in terms of the twenty-five new referents, one referent and its related statements of need per page.

In addition, to give council members a sense at a glance of which goal statements each local committee generated and of the priorities they assigned to each goal statement, a two-dimensional matrix can be developed which lists the twenty-five new referents and their 100 associated goal statements down the left side, each coded for easy reference to the already-described booklet of statements, and the ten regions of the state across the top of the matrix. As appropriate, the rank-order of each statement can then be indicated in the cells of the matrix. (See Appendix B for a sample display of data in such a matrix.)

A second matrix that may be useful for a state council to have during its deliberation on statewide goals and priorities relates the twenty-five new referents to the sixteen service areas usually identified in discussions and legislation relevant to the developmentally disabled. Referents can be arrayed down its side, the sixteen service areas can be listed across its top, and checks or "x's" can be used to indicate which referents or goal statements speak to which service areas.

Given all this information -- the booklet of goal statements organized in terms of twenty-five referents, the matrix of regional priorities, and the matrix of regional goals related to service areas -- state council members can then be asked (1) to focus on the twenty-five referents, (2) to argue for their relative importance, and (3) to identify by a rating or ranking procedure the ten most critical of those twenty-five referents. Naturally, the local goal statements related to each referent help to "unpack" it, but council members should be urged to rank-order the referents in terms of their general content rather than in terms of specific assertions incorporated in any one of the related goal statements. In effect, therefore, council members can be asked to select from the list of twenty-five referents those ten referents that they think are most worthy of being developed into state goals. Any number of processes can be used; for instance, all twenty-five referents can be rated, a "score" developed for each, and the top ten scores identified, or participants can be asked to select five of twenty-five referents and frequency-of-selection scores can be used to identify the top ten referents; or successive rounds of rating or ranking for importance can gradually reduce the list from twenty-five to ten referents.

However handled, once the top ten referents have been identified, the members of the state council can be divided into ten small groups. Each group can be assigned one of the ten referents and charged to develop, from the one or more regional goal statements related to that referent and reported in the booklet, a single expanded statement of need that best describes the specific state need or goal. In so doing, council members may or may not want to revise slightly the original referent, but they most assuredly will want to pick selectively from the assertions of "what is" and "what is preferred" found in the booklet of local goal statements. Eventually, each small group should be able to prepare an entirely new state-oriented, expanded statement of need, one that takes its cues from the statements generated by local groups and includes a referent and comparable assertions in paragraph form of "what is" and "what is preferred."

Assuming that each subgroup has prepared its particular goal statement in reproducible form -- on acetates, with carbon copies, or on ditto masters -- the ten new expanded goal statements can be presented to the total state council. As before in the local groups, these new expanded statements of need should then be processed for interpersonal understanding and acceptance as well as for distortion of the original statements provided by the local groups.

Finally, when all ten goal statements have been processed, exercises similar to those described earlier can be employed by the state council to rate and/or rank-order the list of ten goals, resulting eventually in a set of state priorities for the ensuing year. The product of this second alternative, therefore, is essentially the same as that of the first alternative. The second assumes, however, that the state council will build on inputs from local committees; the first assumes that the council either cannot obtain or does not want to consider those local inputs.

Modifying or Refining an Existing Set of Statewide Goals and Priorities

Once a state council has identified its initial set of goals and priorities in the form of a referent and comparable statements of "what is" and "what is preferred," it has taken a long step toward evaluating achievement of those goals. As explained in some detail in the next section of this report, the council's immediate task is to gather baseline data on the current state of each goal, so that when follow-up data are gathered at the end of the year on the same goals, council members can determine the extent to which progress has in fact been made toward their achievement.

Thus, each year, council members can modify and/or add to last year's goals and priorities on the basis of (1) evaluative data about achievement of last year's goals and (2) another round of inputs from local DD committees. One way to do this would be simply to replicate the processes employed the first year to define goals and priorities. As an alternative, those original processes can be adjusted in such a way that (1) a prior year's goals can be carried forward -- but with evaluative data available about each -- (2) new goals can be added, and (3) the total list of both new and old goals can be reduced systematically to a set of five or seven or ten highest priority goals. Clearly, the specific processes designed each year to modify a state council's set of goals and priorities will have to depend largely on its success in achieving last year's goals, the availability of inputs from local committees, and the decision of council members to build upon the past or to start fresh each year.

ROLE OF THE STATE DEVELOPMENTAL DISABILITIES COUNCIL IN EVALUATING ACHIEVEMENT OF ITS GOALS

Background and Context

The evaluation strategy developed in this project for use by state developmental disabilities councils assumes that planning and evaluation are inseparable components of a cyclical process. Planning lays the foundation for evaluation by specifying the goals and objectives that must be measured. Evaluation influences subsequent planning efforts by documenting the extent to which goals and objectives have been achieved.

A critical requirement of this evaluation strategy is that a need be defined as the discrepancy between an existing state of affairs and a desired state of affairs. This definition of a need leads to a stylized method of stating goals, whereby each goal consists of three components: a referent indicating the subject matter of the goal; a designative statement indicating the current state of affairs with respect to that referent; and an appraisive statement indicating the desired state of affairs.

Once goal statements have been formulated in this fashion, evaluation can be construed as a three-step process occurring over an extended period of time: (1) ascertaining the accuracy of the designative statement for each goal shortly after the goal has been adopted, and using this information for a baseline evaluation report; (2) ascertaining any progress with respect to the designative statement after the passage of a period of time; and (3) examining the remaining discrepancy between the actual and preferred state of affairs. Results from steps two and three can be utilized in a follow-up evaluation report.

Implementation of the Strategy

The development of a baseline evaluation report begins with a careful examination of a state council's established goals and priorities. The designative component of each goal statement must be empirically examined in order to ascertain its truth or falsity. Any of three possible conclusions may result from the initial inquiry: (1) Available data are fully adequate to confirm the designative component of the goal statement; (2) Available data are not fully adequate; or (3) No data available are relevant to the goal statement.

When adequate data are available, it is possible, of course, to verify immediately the designative component of a given goal statement. When no relevant data are available, it is necessary to design and implement a strategy for collecting such data before the designative statement can be verified. When available data are only partially adequate, a decision must be made whether to use these available data or to generate additional data as well.

Once the status of the designative component of a given goal has been confirmed, it is then possible to examine the discrepancy between the actual and preferred state of affairs. An assessment of this discrepancy constitutes the core of a baseline evaluation report. This initial report serves two purposes: (1) it provides an empirical foundation for encouraging agencies and programs to attend to particular unmet needs of developmentally disabled people; and (2) it provides a benchmark against which to measure future progress with respect to each adopted goal. Figure 1 presents a flowchart of the procedures that have just been discussed for verifying the designative component of a goal statement and assessing discrepancies between the actual and preferred state of affairs.

Prior to submitting its next annual plan, a state council should prepare a follow-up evaluation report assessing progress with respect to each previously adopted goal. Preparation for this report, however, should begin immediately following completion of the baseline report.

One of the products of the baseline report will be an awareness of certain inadequacies in the data that have been collected. Such awareness should serve to stimulate the designing of improved data collection procedures prior to conducting the follow-up evaluation. It may be necessary to establish one or more task forces to investigate a variety of data collection alternatives.

Once the data collection strategies have been determined and sufficient time has elapsed for progress to occur, follow-up data should be collected concerning the designative component of each goal. Examination of this follow-up data in juxtaposition with comparable baseline data will permit an evaluation of whether or not progress has been made with respect to each adopted goal. Further examination of the discrepancy between the new actual state of affairs and the preferred state of affairs will also provide an evaluation of the progress that still remains to be achieved. The follow-up evaluation report should then be used to influence the state developmental disabilities council as it determines its goals and priorities for the next year. A flowchart summarizing these procedures for follow-up evaluation can be found in Figure 2.

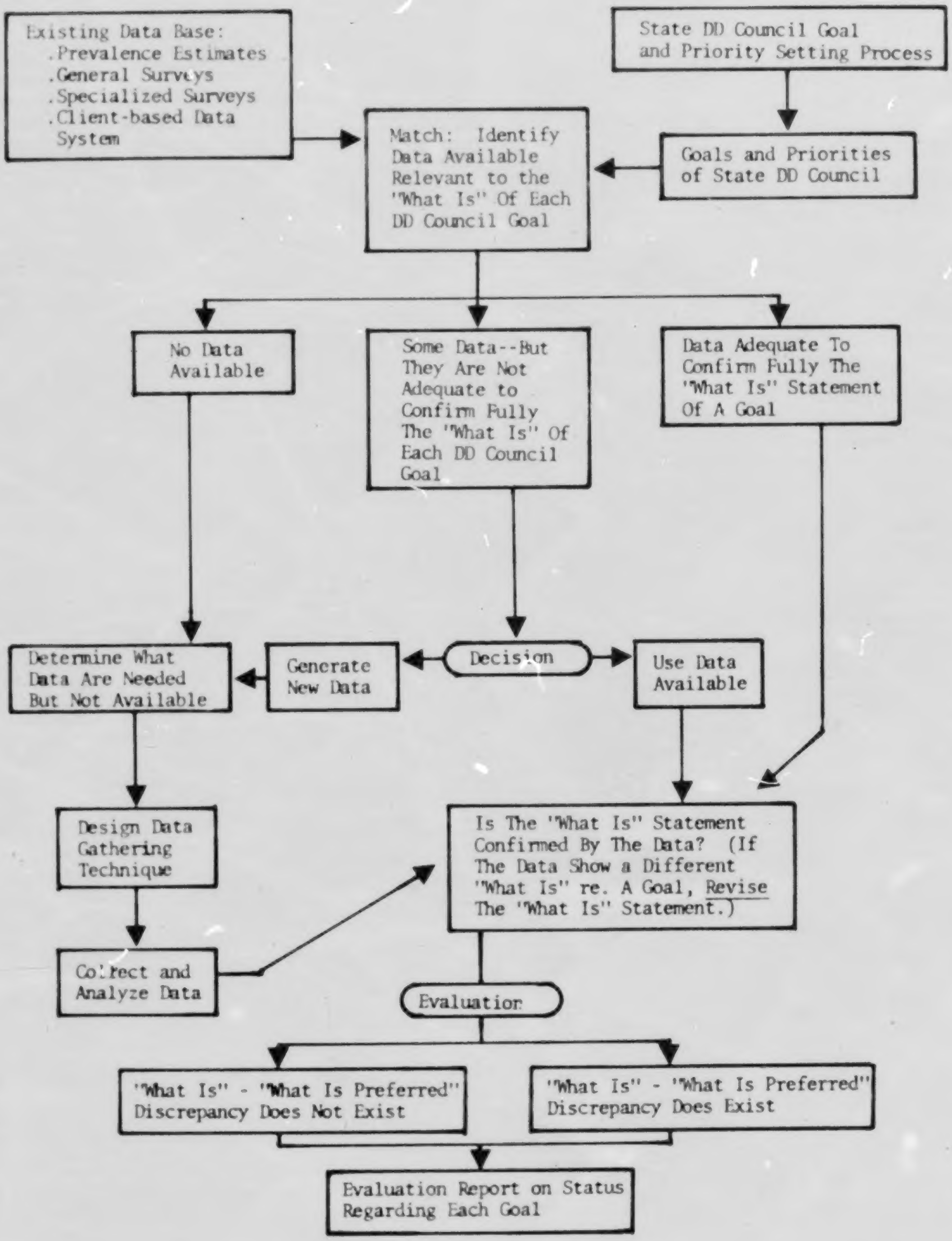

Existing Data Base:
.Prevalence Estimates
.General Surveys
.Specialized Surveys
.Client-based Data System
State DD Council Goal and Priority Setting Process
Match: Identify Data Available Relevant to the "What Is" Of Each DD Council Goal
Goals and Priorities of State DD Council
No Data Available
Some Data--But They Are Not Adequate to Confirm Fully The "What Is" Of Each DD Council Goal
Data Adequate To Confirm Fully The "What Is" Statement Of A Goal
Determine What Data Are Needed But Not Available
Generate New Data
Decision
Use Data Available
Design Data Gathering Technique
Collect and Analyze Data
Is The "What Is" Statement Confirmed By The Data? (If The Data Show a Different "What Is" re. A Goal, Revise The "What Is" Statement.)
Evaluation
"What Is" - "What Is Preferred" Discrepancy Does Not Exist
"What Is" - "What Is Preferred" Discrepancy Does Exist
Evaluation Report on Status Regarding Each Goal

FIGURE 1
Flowchart of BASELINE Evaluation

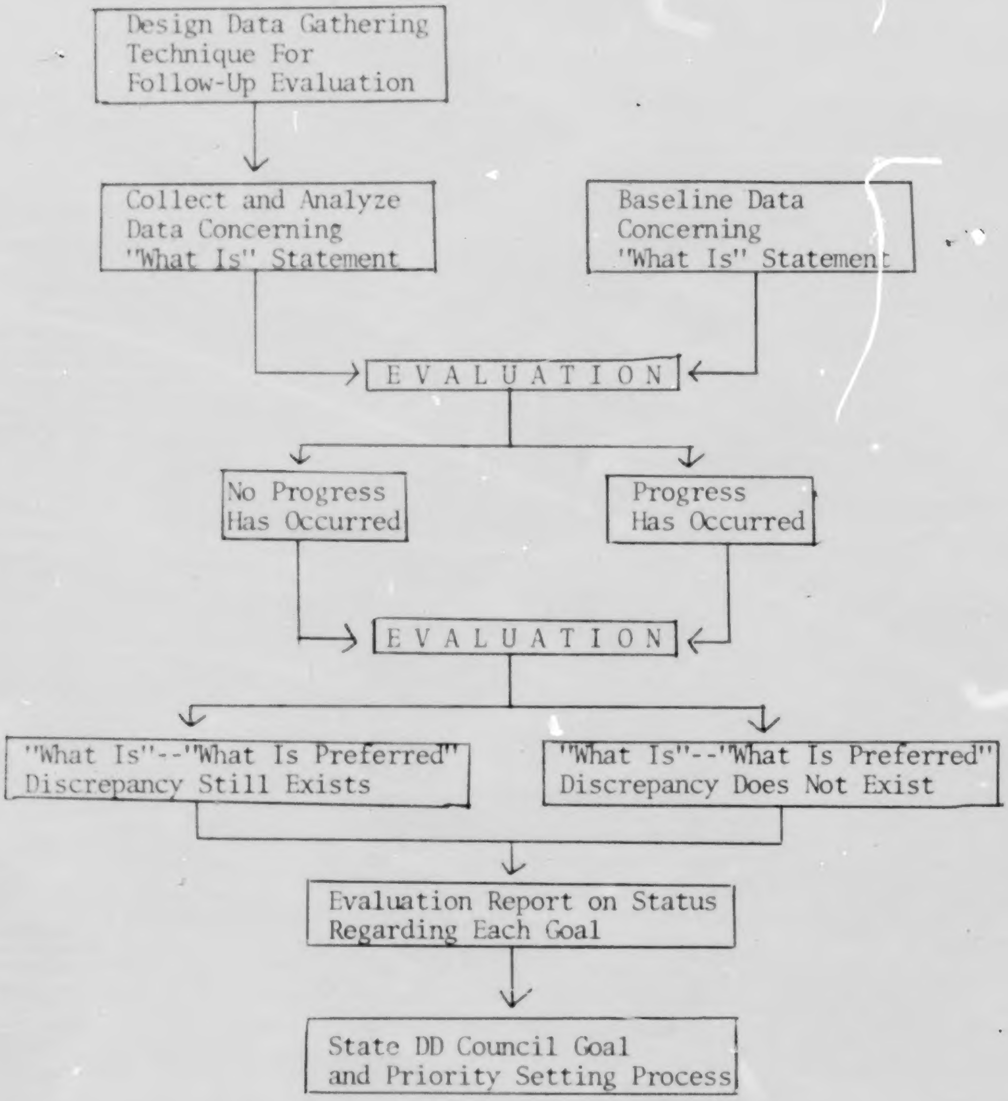

Design Data Gathering Technique For Follow-Up Evaluation
Collect and Analyze Data Concerning "What Is" Statement
Baseline Data Concerning "What Is" Statement
EVALUATION
No Progress Has Occurred
Progress Has Occurred
EVALUATION
"What Is"--"What Is Preferred" Discrepancy Still Exists
"What Is"--"What Is Preferred" Discrepancy Does Not Exist
Evaluation Report on Status Regarding Each Goal
State DD Council Goal and Priority Setting Process

Figure 2
Flowchart of Follow-Up Evaluation

Although it is clear that the processes of planning and evaluation are cyclical in nature, the length of an individual cycle may be somewhat arbitrary. A developmental disabilities council will probably follow a one-year cycle since the law requires that state plans be evaluated and revised on an annual basis.

Figure 3 portrays the major events in such a cycle over a two year period. As can be seen from this flow chart, a separate activity of baseline evaluation is required only for new goals that emerge during the goal setting process. When an old goal is readopted for a subsequent year, follow-up information from the previous year can serve as baseline data against which to measure any progress that may be revealed from follow-up information collected during the subsequent year.

Some Simulation Exercises

The flow charts and accompanying discussion just presented can be used in an introductory lecture to council members on this strategy for evaluation, provided they have been previously introduced to the planning concepts which constitute a foundation for the cycle. In addition to a formal lecture, however, it may be useful to provide council members with a more experiential frame of reference for understanding the issues and complexities of the evaluation process. Toward this end, a number of simulation exercises have been developed.

In addition to providing an opportunity for experiencing the evaluation process vicariously, the simulation exercises were designed to stress especially the following points: (1) Baseline data should be gathered soon after adoption of a set of goals; (2) Careful evaluation of adopted goals will influence goal setting procedures in subsequent years; (3) The identification and gathering of high quality data for evaluation is partially the responsibility of council members; and (4) Different types of goals require different kinds of evaluative data.

In order to illustrate this fourth point, three simulation exercises were developed, each requiring a different kind of data. The first exercise illustrates a goal in which agencies providing services are the appropriate "subjects" for data collection. The second exercise illustrates a goal in which the clients receiving services are the appropriate subjects. The third exercise illustrates a goal in which people other than clients are the appropriate subjects. Examining these three exercises together illustrates the point that no single data collection format will be suitable for evaluating all types of goals.

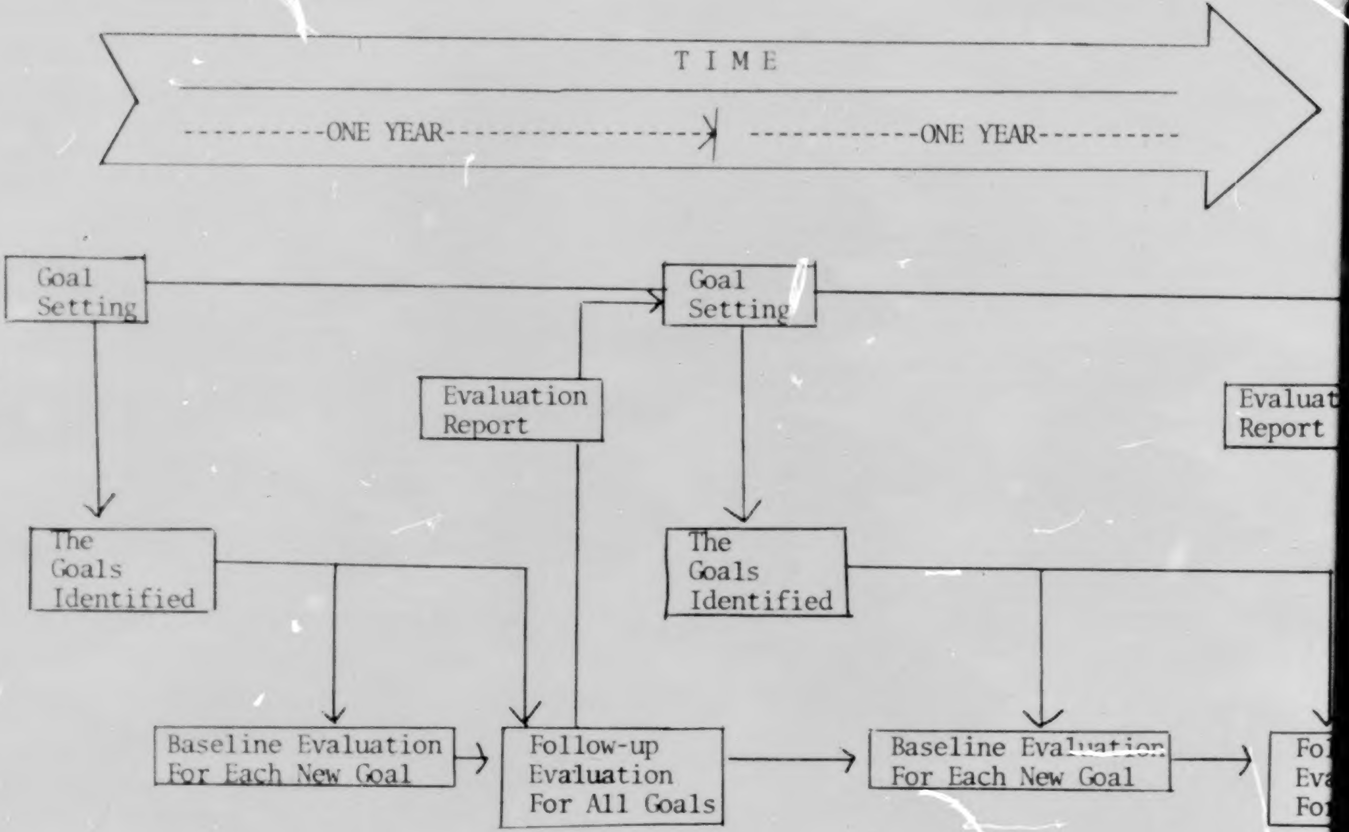

TIME
----------ONE YEAR------------------
------------ONE YEAR----------
Goal Setting
Goal Setting
Evaluation Report
Evaluat Report
The Goals Identified
The Goals Identified
Baseline Evaluation For Each New Goal
Follow-up Evaluation For All Goals
Baseline Evaluation For Each New Goal
Fol Eva For

Figure 3
Timeline For Evaluation Cycle

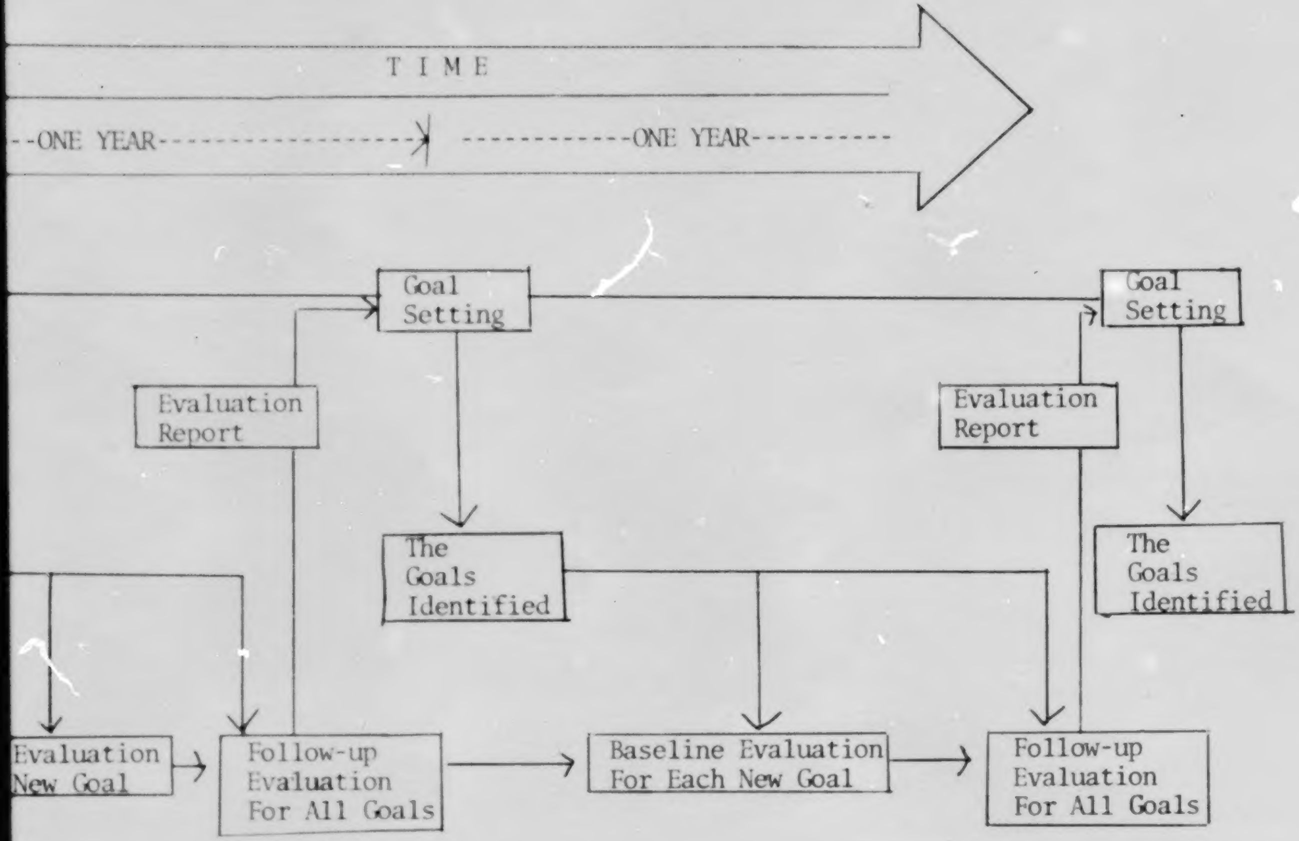

T I M E
--ONE YEAR--
--ONE YEAR--
Goal Setting
Evaluation Report
The Goals Identified
Evaluation New Goal
Follow-up Evaluation For All Goals
Baseline Evaluation For Each New Goal
Follow-up Evaluation For All Goals
Goal Setting
Evaluation Report
The Goals Identified

Figure 3
Timeline For Evaluation Cycle

The three exercises refer to goals of high priority to the Oregon Developmental Disabilities Council, in order to maximize the believability and relevance of the exercises and, hopefully, the lessons to be learned from them. With this in mind, the exercises are presented here only as examples. Others wishing to engage in similar activities should probably devise their own exercises in order to ensure that the material will be attractive to their own council members.

The following exercises presented to Oregon Council members make reference to a File of Background Data and to Charts I, II, and III. The charts are reproductions of Figures One, Two, and Three presented above. The File of Background Data contained Oregon's 1973 State Plan, some data collection forms that are being proposed for adoption in Oregon, and a contrived memorandum providing data with respect to one of the exercises. The File has not been reproduced here because of space limitations.

Exercise One

The highest priority goal established by the Oregon DD Council last year was not phrased as a goal referent, statement of "what is" and a comparable statement of "what is preferred." However, it was relatively easy to translate that goal into this format.

GOAL REFERENT: Fixed Point of Referral Services

GOAL STATEMENT:

What is: There are no centrally located agencies in the state -- fixed point of referral centers -- that are designed (1) to help the developmentally disabled and their families get to and make use of existing services, (2) to provide information to developmentally disabled people and the general public, and (3) to maintain a central registry of developmentally disabled people and the services available to them.

What is preferred: We prefer that centers able to meet the above needs -- fixed point of referral centers -- be established throughout the State of Oregon.

Task #1: Given the above goal statement, the File of Background Data, and Charts I, II, and III, attempt to determine:

a. the "What Is" state of the goal at the time of its adoption;
b. the current "What Is" state of the goal; and
c. the specific data, if any, that may still be needed for an adequate evaluation of movement during the past year toward achievement of the goal.

Task #2: Prepare a brief evaluation report on the status of the goal today for presentation at tomorrow's State DD Council meeting when goals and priorities will be set for next year.

Task #3: Assume that during the State DD Council session you are asked to prepare for presentation after lunch a revised statement of a Fixed Point of Referral goal for Council consideration as a high priority goal next year. Prepare the statement as you would submit it to the afternoon Council session.

Task #4: Assume that two weeks have elapsed since the State DD Council met and established its goals and priorities and that you are now involved in a DD Council Executive Committee meeting called to ensure that adequate baseline data are established for each high priority goal. In addition, assume that the goal statement you prepared in Task #3 continues to be one of the state's high priority goals.

Given the revised goal statement, the File of Background Data, and Charts I, II, and III, prepare a directive to the staff of the State DD Council indicating the specific kinds and sources of baseline data that should be collected with respect to this goal.

Exercise Two

One great concern expressed by those who help developmentally disabled people is their need for alternative living facilities. Therefore, it seems plausible that the following goal would be adopted as a high priority of the State DD Council for next year.

GOAL REFERENT: Alternative Living Facilities

GOAL STATEMENT:

What is: Alternative living arrangements for developmentally disabled people are extremely limited. Specifically, there is a lack of group homes, foster homes, halfway houses, and other noninstitutional living facilities to provide care and independent living opportunities. Existing facilities are often inconveniently located, are not prepared to deal with certain disabilities (such as emotional disturbances or multiple handicaps), and usually do not provide regular social and educational activities. In addition, their supervisors are often poorly trained and badly paid.

What is preferred: We prefer that a variety of noninstitutional, homelike living arrangements be available so that developmentally disabled people can live as independently and actively as possible. We also prefer that these facilities be centrally located and integrated with community educational, vocational, recreational, and transportation services. Finally, we prefer that adequate pay be provided for well-trained and certified individuals to supervise these facilities.

Task: Assume that two weeks have elapsed since the State DD Council met and established this as one of its high priority goals. You are now involved in a DD Council Executive Committee meeting called to ensure that adequate baseline data are established for each high priority goal.

Given the goal statement, the File of Background Data, and Charts I, II, and III, prepare a directive to the staff of the State DD Council indicating the specific sources of baseline data that should be collected with respect to this goal.

Exercise Three

Great concern has been voiced about the attitudes of the public with respect to developmentally disabled people. Therefore, it seems plausible that the following goal would be adopted as a high priority of the State DD Council for next year.

GOAL REFERENT: Attitudes of Others Toward the DD

GOAL STATEMENT:

What is: The general public tends to devalue and discriminate against persons with developmental disabilities. It is often uninformed and apathetic about the problems of handicapped groups. For example, there are a number of myths and misconceptions about epileptics, often the result of a lack of understanding and knowledge about the disability; moreover, the noticeably physically handicapped are often rejected simply on the basis of their disabilities.

What is preferred: We prefer that in an effort to increase public understanding there be more dissemination of information about the capabilities as well as the limitations of developmentally disabled people... that handicapped persons be evaluated on their own merits, regardless of their particular disability... and that widespread myths and misconceptions -- particularly with respect to epilepsy -- be dispelled by public education in an effort to increase public understanding and acceptance.

Task: Assume that two weeks have elapsed since the State DD Council met and established this as one of its high priority goals. You are now involved in a DD Council Executive Committee meeting called to ensure that adequate baseline data are established for each high priority goal.

Given the goal statement, the File of Background Data, and Charts I, II, and III, prepare a directive to the staff of the State DD Council indicating the specific kinds and sources of baseline data that should be collected with respect to this goal.

Appendix A

1. Developmental Disabilities Planning and Advisory Council Membership
2. State Council September Workshop Agenda
3. State Council April Workshop Agenda

Developmental Disabilities Planning and Advisory Council Membership

E. E. Balsiger
Consumer Representative
Oregon Association for
Retarded Children
Klamath Falls, Oregon

Allison Belcher
Consumer Representative
Portland, Oregon

Barton Brown
Consumer Representative
Pacific Northwest Bell
Portland, Oregon

Zane Campbell*
Consumer Representative
Omark Industries, Inc.
Portland, Oregon

Norman Crawford
Consumer Representative
United Cerebral Palsy of
Oregon

Harold D. Fredericks, Ph.D.
Higher Education
Teaching Division, Oregon
College of Education
Monmouth, Oregon

Andrew S. Halpern, Ph.D.
Higher Education
Rehabilitation Research and
Training Center in Mental
Retardation
University of Oregon
Eugene, Oregon

Tom Higley
Consumer Representative
Oregon Association for
Retarded Children
Pendleton, Oregon

Jeffrey Johnston
Consumer Representative
Portland, Oregon

Linda Kiever
Consumer Representative
United Cerebral Palsy
Salem, Oregon

David D. Kullowatz, D. D.
Consumer Representative
Oregon Association for
Retarded Children
Salem, Oregon

William Lowther
Provider Representative
Public Assistance Division
Salem, Oregon

David MacFarlane, M. D.
Provider Representative
University of Oregon Medical
School
Portland, Oregon

Richard J. Mathewson, D.D.S.
Consumer Representative
United Cerebral Palsy Association
Portland, Oregon

*Member, Executive Committee

Jerry McGee, Ph.D.*
Consumer Representative
Oregon Association for
Retarded Children
Salem, Oregon

Richard S. Mitchell, Ph.D.*
Consumer Representative
United Cerebral Palsy Association
Portland, Oregon

Dean Orton
Provider Representative
Children's Services Division
Salem, Oregon

Rhesa Penn, M.D.
Provider Representative
Department of Human Resources,
Health Division
Portland, Oregon

James Pomeroy, M.D.*
Provider Representative
Mental Retardation Services
Salem, Oregon

Ray Rothstrom
Provider Representative
Oregon Board of Education
Salem, Oregon

Robert Schwarz, Ph.D.
Provider Representative
Center on Human Development
University of Oregon
Eugene, Oregon

Norman Silver
Provider Representative
Department of Human Resources,
Vocational Rehabilitation
Division
Salem, Oregon

Bette Stokes*
Consumer Representative
Epilepsy League of Oregon
Portland, Oregon

Hazel Warren*
Provider Representative
Comprehensive Health Planning
Association for Portland
Metropolitan Area
Portland, Oregon

James M. Watson, M.D.*
Consumer Representative
Epilepsy League of Oregon
Portland, Oregon

Helen White
Consumer Representative
Comprehensive Health Planning
Agency
Coos Bay, Oregon

Health Planning Staff

David Porter
DD Planner
Office of Comprehensive Health
Planning
Salem, Oregon

Ruth Russell
DD Planner
Office of Comprehensive Health
Planning
Salem, Oregon

*Member, Executive Committee

State Council September Workshop Agenda

Thursday, September 14

Registration and warmup

Friday, September 15

- ° Introductory comments
- ° What is planning and what is evaluation?
- ° Review of current data available to state council and its staff
- ° Lunch
- ° Presentation and discussion of a strategy for generating state goals and priorities

Saturday, September 16

- ° Initial generation by the council of some potential state goals
- ° Lunch
- ° Establish potential state priorities from among the generated goals

State Council April Workshop Agenda

Friday, April 13

- Lunch
- Executive committee evaluation simulation exercise

Saturday, April 14

- Registration
- General review of the planning and evaluation project
- Presentation and discussion of the results from the local workshops and survey goal-generating activities
- Lunch
- Establish state goals and priorities for the 1973 state plan

Appendix B

1. Materials Developed to Assist the State Council in Their Needs Assessment and Goal Setting Activities:
    a. A Summary of Goal Referents, Goal Statements, Procedures, Groups, and Group Priorities
    b. A Master List of Top Priority Goal Referents and Related Goal Statements Relevant to Oregon's Developmentally Disabled
2. A Complete List of the Eleven Expanded Problem Statements Adopted by the Oregon State Council for Use in the State Plan

BEST COPY AVAILABLE

A SUMMARY OF GOAL REFERENTS, GOAL STATEMENTS, PROCEDURES, GROUPS, AND GROUP PRIORITIES (April 1973)

Presented below is a cumulative list of thirty-three "top priority" goal referents and the number(s) of their related goal statements. These have been generated by eleven different groups in the state of Oregon and are presented here as potential State DD Goals for 1974. For the complete goal statements, please refer to the accompanying Master List.

Indicated below are (1) the general procedures employed to generate the goal statements, (2) the size and nature of the eleven groups, and (3) each group's top priority goal statements in order of importance.

These priorities were produced by a Modified Delphi Investigation--Needs Assessment, requiring three cycles of mailouts and involving a total of...

Goal Referent	Number of Related Goal Statement(s)	221 Practitioners in Oregon's Fourteen Geographic Regions...**					56 Experts in the Fields of...			These priorities were produced by one-day small-group workshops involving a total of 71 Consumers, Practitioners, and Others in...		
		Reg. 1, (N=38)	Reg. 2 (N=56)	Reg. 4, (N=31)	Reg. 6- (N=47)	Reg. 9-14 (N=49)	MR (N=23)	CP (N=16)	Epil. (N=17)	Reg. 2 (N=25)	Reg. 5 (N=23)	Reg. 10 (N=23)
1.0 Attitudes of the DD toward themselves	1.1*											
2.0 Attitudes of the general public toward the DD	2.1	8- 9	11	10-11	2- 3	7	3- 5		2- 3			
	2.2										6- 7	
3.0 Attitudes of employers toward the DD	3.1										12	
4.0 Attitudes of insurance companies toward DD	4.1*											
5.0 Personal rights of the DD	5.1*											
6.0 Architectural barriers to the DD	6.1									10		
	6.2							10-12				
7.0 Funds for providing services for the DD	7.1	12	9	10-11	7- 8	6	3- 5		4			
	7.2									2- 3		
	7.3											8
8.0 Basic research relevant to the DD	8.1*											
9.0 Knowledge and training of physicians who serve the DD	9.1								2- 3			
10.0 Knowledge and training of non-physicians who serve the DD	10.1						11-12					
11.0 Identification of the DD	11.1										5	
	11.2*											
12.0 Diagnostic and evaluative services for the DD	12.1											1
	12.2											9
	12.3								1			
13.0 Coordination of services for the DD	13.1											3- 4
	13.2									6		
	13.3										2- 3	
	13.4	10-11	5- 7	7- 9	7- 8	11-12	2	3- 5	5-10			
14.0 Local availability of services for the DD	14.1											5
	14.2					5						
15.0 Transportation services for the DD	15.1							2				
	15.2									4- 5		
16.0 Training for the DD with respect to basic living skills	16.1	5	1	4	6	2- 3	11-12	10-12				
17.0 Treatment for the emotionally disturbed DD	17.1	6- 7	10	7- 9	10							
18.0 Treatment for epileptic seizures	18.1								5-10			
19.0 Services for pre-school DD children	19.1										10-11	
	19.2	10-11	5- 7	7- 9		11-12	9-10	10-12	5-10			
20.0 Services for post-school DD adults	20.1										6- 7	
	20.2	3- 4	5- 7	5- 6	4- 5	10	6- 8					
21.0 Alternative living arrangements for the DD	21.1									1		
	21.2										1	
	21.3											3- 4
	21.4	1- 2	2	3	2- 3	1	1	1				
22.0 Financial income for DD adults	22.1							6- 9				
23.0 Job training for the DD	23.1											7
	23.2	1- 2	3	1	4- 5	4	6- 8	6- 9	5-10			
24.0 Job opportunities for the DD	24.1									2- 3		
	24.2											2
	24.3									4- 5		
	24.4	3- 4	4	2	1	2- 3	3- 5	6- 9	5-10			
	24.5										10-11	
25.0 General education programs for DD children	25.1									7- 9		
	25.2	6- 7			9	8	6- 8					
26.0 Physical education programs for DD children	26.1*											
27.0 Educational programs for DD children with special learning disabilities	27.1*											
28.0 Educational programs for TMR children	28.1*											
29.0 Educational programs for EMR children	29.1		12									
30.0 Social and recreational activities for the DD	30.1											6
	30.2			12				3- 5				
31.0 Counseling and training services for families of the DD	31.1									7- 9		
	31.2	8- 9		5- 6	12	9		3- 5				
	31.3										4	
	31.4		8		11		9-10	6- 9	5-10			
	31.5										9	
32.0 Financial assistance to families of the DD	32.1										2- 3	
	32.2*											
33.0 Respite services for the DD and their families	33.1*											
	33.2											10
	33.3									7- 9		
	33.4										8	

*Each of these goal statements was generated during the Modified Delphi Investigation and processed for "ratings" of importance by one or more of the eight groups involved in that investigation; none of these statements surfaced, however, as a top priority goal of any of the groups.

**For purposes of the survey, given relatively small populations in some regions of the state, responses were tabulated and analyzed in terms of five groups of regions. Thus, the priorities for Regions 1 and 3 are the same, as are the priorities for regions 4 and 5, and so forth.

A Master List of Top Priority Goal Referents and Related Goal Statements Relevant to Oregon's Developmentally Disabled

1.0 Attitudes of the DD Toward Themselves

1.1 What is: Many DD individuals poorly understand their handicap, often believing that, because of it, they cannot marry, hold a job, or participate in normal social activities. Many also feel stigmatized and therefore attempt to keep their condition a secret.

What is preferred: We prefer that each DD individual be helped to understand both his disorder and his unique abilities, that he openly admit his condition, and that he seek assistance.

2.0 Attitudes of the General Public Toward the DD

2.1 What is: The public, while often solicitous, does not generally understand the developmentally disabled or accept them as full-fledged members of the community; rather, it tends to overemphasize their shortcomings and ignore their potential for growth. Worse, the fears and misconceptions the public harbors are manifested in extensive social prejudice against the DD, who, as its victims, suffer ridicule, humiliation, and rejection. Families, associates, and professionals who deal with the DD are by no means innocent of such prejudices.

What is preferred: We prefer that the public -- including parents, associates, employers, teachers and other service workers -- understand and accept the needs and abilities of the DD. State agencies, public schools, and the media might cooperate in programs to teach the public ways of helping the DD and to encourage community interaction with the DD.

2.2 What is: The general public tends to devalue and discriminate against persons with developmental disabilities. It is often uninformed and apathetic about the problems of handicapped groups. For example, there are a number of myths and misconceptions about epileptics, often the result of a lack of understanding and knowledge about the disability; moreover, the noticeably physically handicapped are often rejected simply on the basis of their disabilities.

What is preferred: We prefer that in an effort to increase public understanding there be more dissemination of information about the capabilities as well as the limitations of the DD . . . that handicapped persons be evaluated on their own merits, regardless of their particular disability . . . and that widespread myths and misconceptions of the DD -- particularly with respect to epilepsy -- be dispelled by public education in an effort to increase public understanding and acceptance.

3.0 Attitude of Employers Toward the DD

3.1 What is: Many employers are reluctant to hire the DD. As a result, for example, epileptics find they need to conceal their disability during job interviews.

What is preferred: We prefer that there be equal opportunity --no discrimination--for the DD in appropriate areas of the job market . . . that disclosure of an epileptic's disability not prejudice his employment opportunities.

4.0 Attitudes of Insurance Companies Toward the DD

4.1 What is: Insurance companies often discriminate against the DD, either by simply refusing them coverage or by charging high premiums for limited coverage.

What is preferred: We prefer that insurance be regulated so as to be available to all qualified DD individuals, and at reasonable rates.

5.0 Personal Rights of the DD

5.1 What is: The rights and wishes of the DD who live in group or nursing homes are not always protected. Unscrupulous home operators may exploit them, for example, by using or withholding their personal allowances, controlling their medication, or keeping them in a home against their will.

What is preferred: We prefer that DD clients be protected against exploitation by care providers. Where a patient is unable to determine his rights, protection should be provided --caseworkers could be given more power to protect their clients, for example.

6.0 Architectural Barriers to the DD

6.1 What is: The majority of public and private buildings, including low cost housing, are physically inaccessible to the physically handicapped. Legislation relevant to this now applies only to new, state-owned buildings.

What is preferred: We prefer that all buildings, including low cost housing, be designed for easy entrance, exit, and usability by the physically handicapped . . . furthermore, that legislative and funding constraints be enacted to make all facilities accessible to the physically handicapped.

6.2 What is: Architectural barriers, such as stairways without ramps or doorways too narrow for wheelchairs, restrict the mobility and thus the independence of the DD. Even new or remodeled buildings are constructed without consideration for the disabled.

What is preferred: We prefer that the needs of the DD be considered in the design of major public buildings. Special safety and convenience features, such as ramps and elevators, should be provided wherever possible so that disabled can use these buildings.

7.0 Funds for Providing Services for the DD

7.1 What is: Funds for the provision of services to the DD are generally inadequate. This is sometimes because the DD are low on the priority list for available money. In other instances, money allocated for the DD is deposited in an agency's general fund and then spent for other purposes. The mechanisms for funding programs are also frequently clumsy and ineffective. For example, one agency may need to apply to numerous sources in order to get sufficient funds for a single program. Moreover, money that is awarded often carries inappropriate restrictions concerning the types of DD people that are eligible, and frequently the announcement of awards comes too late for effective planning.

What is preferred: We prefer that more local, state, and federal funds be made available for increasing and improving programs for the DD; that specially designated funds for the DD be used only for their intended purposes; that consistent methods of appropriating funds be developed, with as few restrictions as possible on the types of DD persons eligible; and that grant awards be announced far enough in advance for effective planning and implementation.

7.2 What is: There is a lack of public money for implementing programs and services. Prior legislatures did not always give high priority to the problems of the DD. The lack of funds prevent some DD from obtaining adequate medication and equipment.

What is preferred: We prefer that there be sufficient funds to implement programs . . . that the next legislature be more sympathetic to the financial needs of the DD . . . that there be adequate funds to modify or ameliorate medical and equipment needs of the DD, e.g., a medication/equipment bank especially for developmentally disabled individuals.

7.3 What is: Some regions do not receive their fair share -- based on need and population -- of Oregon's state and local funds for the DD. For example, only two of fifteen grant proposals submitted from Central Oregon during the past three years have been funded.

What is preferred: We prefer that funds for the DD from state and federal sources be more fairly allocated on the basis of population and need in each area of the state.

8.0 Basic Research Relevant to the DD

8.1 What is: Knowledge of the functions of the brain (both general and specific) is extremely limited.

What is preferred: We prefer that basic research into the functions of the brain be accelerated, and that such research ultimately provide information useful in diagnosing and treating specific brain disorders.

9.0 Knowledge and Training of Physicians Who Serve the DD

9.1 What is: Many physicians are not well informed about the diagnosis and treatment of developmental disabilities (especially seizure disorders). Moreover, they are usually not trained to counsel DD patients about the psychosocial aspects of their disorders.

What is preferred: We prefer that physicians be well informed and skilled in the diagnosis and treatment of developmental disorders and in the counseling and DD patients.

10.0 Knowledge and Training of Non-Physicians Who Serve the DD

10.1 What is: Those who serve the DD often lack the knowledge, understanding, and training to meet the needs of the DD. For example, many teachers and administrators have had insufficient exposure (in university courses or in practicums) to the methods and purposes of special education; teachers often do not understand problems in emotional or physical development; administrators frequently lack interest; and many care providers do not have the training to provide stimulating home environments.

What is preferred: We prefer that DD persons be served by knowledgeable, understanding people who are aware of the needs of the DD and who have the desire and skills to meet these needs. There should be cooperative programs (between agencies and universities, for example) to educate service workers about the DD, and to encourage them to take an interest in the problems of the DD, and to give them training in recognizing and alleviating problems.

11.0 Identification of the DD

11.1 What is: There is currently little or no effort directed toward the early identification of persons with DD, i.e., from birth to age one. Moreover, many of the DD who reside in Oregon are unknown to service agencies and, therefore, receive no services. In addition, there is no one agency charged with the responsibility of identifying and maintaining an updated roster of all the DD in each county.

What is preferred: We prefer that a greater effort be directed toward early identification of the DD . . . that steps be taken to identify the DD in Oregon . . . and that one agency be charged with the responsibility for maintaining a current roster indicating the number and location of potential DD clients.

11.2 What is: In this community, there is little coordinated and responsible effort to screen and identify the DD. Some DD are identified only when they come in contact with public agencies; thus, they sometimes go undetected too long, particularly children who need very early treatment. Children are usually not screened at school entrance, and there is no routine screening of under-achievers by public school teachers.

What is preferred: WE prefer that there be greater effort to identify and locate the DD who do not now receive service; that emphasis be on identifying the preschool DD population; that there be routine testing of potential MRs in the early school years; that efforts be continued to identify the post-school-aged DD; and, that service providers, such as teachers, be better prepared to recognize early problems.

12.0 Diagnosis and Evaluative Services for the DD

12.1 What is: There is currently no diagnostic clinic or research center for the developmentally disabled in our region.

What is preferred: We prefer that a comprehensive diagnostic clinic -- possibly combined with a research center -- be established in a location convenient to our region and that diagnosis attend to the emotional, mental, social and physical needs of the developmentally disabled.

12.2 What is: There are currently no adequate testing programs in our region for evaluating the abilities and talents of the DD -- pre-school abilities, vocational skills, mental aptitude, and so forth.

What is preferred: We prefer that a comprehensive testing program be developed to diagnose and evaluate all facets of a developmentally disabled individual's abilities and skills.

12.3 What is: There is a lack of adequate diagnostic and evaluation services for all age-groups of the DD in our community. Where services are available, insufficient resources (particularly the shortage of trained and experienced professionals) limit the frequency, comprehensiveness, and usefulness of the service. For example, client plans must often be formulated from records too old and vague to be of direct value; good evaluation instruments are lacking; and important client decisions are often made without corroborating evidence.

What is preferred: We prefer that adequate and comprehensive diagnostic and evaluation services be regularly and frequently available to all DD in this community; that these services be provided by trained and competent personnel; that particular emphasis be directed toward the differential diagnosis of the preschool DD population; that more effective evaluation and assessment instruments be developed; and that data from such instruments be corroborated by other available evidence, especially first-hand observation of the clients involved.

13.0 Coordinating of Services for the DD

13.1 What is: There is a general lack of coordination of services to the DD. For example, there is often no follow-through on referrals, with the result that many DD simply get lost "between the cracks."

What is preferred: We prefer that a specialized agency be created to provide comprehensive coordination of the medical, educational, vocational, and other services available to the DD in our region.

13.2 What is: There is no central source of information on available services for the DD, their parents, and providers of services to the DD; as a result, agencies sometimes duplicate services or are unaware of each other's activities.

What is preferred: We prefer that a central information source be made available to the DD, the parents of DD, and those agencies presently providing services to the DD.

13.3 What is: No fixed-point referral is provided; follow-along of the DD is not regular and consistent; some agencies retain clients unnecessarily when they could be better served by another agency; some services are duplicated by many agencies while other services remain unavailable.

What is preferred: We prefer that there be one central agency responsible for coordinating services to the DD . . . and that this agency be client-oriented to provide adequate follow-along for the DD.

13.4 What is: It is very difficult to coordinate care for the DD. For example, there is no fixed person or agency in our community to act as a referral point for them and their families. Without such a service(as things now stand), many do not receive all of the services for which they are eligible. Existing programs frequently suffer from lack of coordination and communication among service agencies and professionals, resulting in fragmented or overlapping delivery of services. Lack of coordination also makes it difficult to plan and provide for a lifetime continuity of services.

What is preferred: We prefer that a fixed person or agency be designated in our community to help DD clients and their families obtain all the services they need throughout their lives. In addition, we prefer that coordination be improved among agencies serving DD.

14.0 Local Availability of Services for the DD

14.1 What is: Most treatment for the DD means removal from the community -- that is, it means having to travel somewhere. For instance, there is no physical rehabilitation center in the area and transportation is not only necessary, but often a problem and an expense.

What is preferred: We prefer that there be local treatment centers in the region; for example, that there be a physical rehabilitation center in our region with adequately trained staff and a sufficient number of resident personnel.

14.2 What is: Special services and facilities for the DD are extremely limited in our community. The alternative of traveling to other communities (sometimes at considerable distances) is expensive and time consuming (especially when emergency services are needed), and removes the individual from family and friends. Furthermore, communication at long distance is frequently ineffective. For example, agency personnel in distant communities sometimes make decisions about DD individuals without really understanding local conditions and needs. Distance also makes obtaining necessary treatment information and records more difficult.

What is preferred: We prefer that a wide range of services be available regionally -- where possible, within our community. When travel to distant communities is still necessary, more effective communication should be established between those facilities and the people they serve in our communities.

15.0 Transportation Services for the DD

15.1 What is: There is inadequate transportation for the DD to and from service agencies, schools, job sites, and social and recreational facilities. Moreover, existing carriers are not adequately equipped to accommodate DD individuals who are severely handicapped and nonambulatory. Rural areas, where the DD tend to be widely scattered, have even fewer and more expensive transportation alternatives than other areas. Many agencies must either budget for private carriers or depend on volunteers.

What is preferred: We prefer that a variety of transportation alternatives be available at convenient times to all DD, regardless of the severity of their handicap, their ability to pay, or their place of residence.

15.2 What is: Public and/or low cost transportation for the DD is limited. Medical and service facilities do not provide year-round transportation to DD clients in need of this service. There is no centralized transportation system available to the DD, and they often have difficulty manipulating present metro transportation systems, e.g., complicated transit maps, unclear bus identification, barriers of the equipment itself, etc.

What is preferred: We prefer that there be more public and/or low cost transportation for the DD...that these facilities and services be better designed and more easily understood...that agencies serving the DD provide year-round transportation...and that centralized transportation systems be established to provide for the special needs of DD passengers.

16.0 Training for the DD With Respect to Basic Living Skills

16.1 What is: DD individuals (especially post-institutional MR's) are often unprepared to function effectively in the community or to cope confidently with the routine activities of daily living. Some lack basic self-care skills (bathing, dressing, etc.), but nearly all are deficient in decision-making and communication skills, as well as in the practical abilities needed to run a home or hold a job without supervision.

What is preferred: We prefer that there be greater program emphasis on providing the DD with the knowledge, training, and experiences necessary for them to develop more effective self-help and social-living skills.

17.0 Treatment for the Emotionally Disturbed DD

17.1 What is: There is limited help available in our community for DD individuals who also suffer from emotional problems. Treatment is expensive and/or scarce, particularly for children and juveniles (whose problems are often manifested in disruptive classroom behavior).

What is preferred: We prefer that better treatment services be available in our community for the emotionally disturbed DD. No one should be denied a service because of its cost; and teachers should have help in dealing with the behavior problems of emotionally disturbed students.

18.0 Treatment for Epileptic Seizures

18.1 What is: Medical control of seizures is not entirely satisfactory. Medication programs are often poorly planned and administered. Moreover, anticonvulsants are too expensive for some, may have unpleasant side effects, and are not always reliable.

What is preferred: We prefer that there be more effective medical programs to control seizures; moreover, that more satisfactory medication be available to all who need it.

19.0 Services for Pre-School DD Children

19.1 What is: There are very few direct services available to DD children under four years.

What is preferred: We prefer that there be a whole range of services available to DD children under four as well as to their parents: more physical therapy, occupational therapy, speech therapy, and preschool experiences as well as more parental education and training.

19.2 What is: There are few programs to provide education, training, and therapy for preschool DD children. There are almost no services for the very young (although remediation should start as early as possible), and existing early education programs segregate the handicapped from the nonhandicapped -- if they accept DD children at all.

What is preferred: We prefer that there be more programs to provide direct early services to preschool DD children. These programs should be integrated as much as possible with regular preschool programs, but should focus on early intervention in areas of developmental as well as academic difficulties, plus providing training in basic self-care and social adjustment.

20.0 Services for Post-School DD Adults

20.1 What is: There are little or no services available to the DD who are beyond high school age. For example, there is no activity center outside the major city in our region.

What is preferred: We prefer that there be a whole range of services available to the DD who are no longer in school: day care services, activity centers, and workshops that provide meaningful remuneration for the DD.

20.2 What is: Very few programs provide educational, social, and vocational training opportunities for the DD who are past school age; moreover, available programs are often inconveniently located. Thus, if a developmentally disabled person does not receive the services he needs by his early twenties, he is often without further options for growth and training.

What is preferred: We prefer that the DD who are beyond school age have a wide variety of publicly supported options for education and training. These opportunities should be provided for an individual until he has reached his maximum competence, no matter how severe his disability.

21.0 Alternative Living Arrangements for the DD

21.1 What is: In our region there are insufficient supervised living situations/facilities, and those that exist lack trained personnel. For example, there are no community-based long-term residential treatment centers; there are limited facilities with trained personnel to provide care on a temporary basis for moderately independent DD children and adults; more specifically, there are few foster homes and most are poorly designed and staffed; there is no supportive assistance for severely handicapped adults who wish to live independently; and there is no housing other than Fairview available for the CP.

What is preferred: We prefer that there be available a wide range of living situations/facilities for the DD in our region...that well trained personnel staff these facilities...that the public be made aware of the need for foster homes...and that HUD provide housing for the DD in each project.

21.2 What is: In our region there are limited alternative living arrangements -- few group homes, foster homes, community homes, etc. -- and so few residential facilities that will promote independent living and/or total living care, particularly for the severely disabled.

What is preferred: We prefer that there be more residential services and more suitable housing for the DD in our region -- that there be more "protective living environments," both permanent and temporary near available services...that there be more group-supervised living facilities...that, to the extent possible, the DD be able to live outside formal institutions.

21.3 What is: There is little available information about community homes or residential centers that are already in operation outside of Central Oregon. Moreover, there are no such facilities available in our region itself for small groups of DD adults who are willing and able to live together under the supervision of trained staff. That is, older DD in the region receive no assistance in the form of domiciliary care, "half-way houses," or homes with surrogate parents that can help them live independently in the community.

What is preferred: We prefer that more information about existing community homes or residential centers be available and that a variety of community homes, "half-way houses," and homes with surrogate parents be available in the major cities of our region.

21.4 What is: Alternate living arrangements for the DD are extremely limited. Specifically, there is a lack of group homes, foster homes, half-way houses, and other noninstitutional living facilities to provide care and independent living experiences for the DD. Existing facilities are often inconveniently located, are not prepared to deal with certain disabilities (such as emotional disturbances or multiple handicaps), and usually do not provide regular social and educational activities. In addition, their supervisors are often poorly trained and badly paid.

What is preferred: We prefer that a variety of noninstitutional, homelike living arrangements be available so the DD can live as independently and actively as possible. I also prefer that these facilities be centrally located and integrated with community educational, vocational, recreational, and transportation services. Finally, I prefer that adequate pay be provided for well-trained and certified individuals to supervise these facilities.

22.0 Financial Income for DD Adults

22.1 What is: Income for the disabled, whether from employment, social security, or public assistance, is very inadequate.

What is preferred: We prefer that income for the disabled be sufficient for them to enjoy life styles that are as normal as possible.

23.0 Job Training for the DD

23.1 What is: It is difficult for many DD to obtain job training. For example, in our region, the only job training workshop for those over sixteen years of age is located in Redmond. Moreover, transportation to and from the Opportunity Center is undependable; as a simple example, the buses are in bad need of repair.

What is preferred: We prefer that at least there be better, more dependable equipment for transporting the DD to and from the Opportunity Center; ideally we prefer that there be more job training workshops in local areas.

23.2 What is: Vocational training programs for the DD are extremely limited. Existing training programs are often irrelevant and/or non-redemptive; many exclude certain disability groups or depend on unreliable "contract work" with private industry; and many are not suited to the needs or talents of the individuals involved.

What is preferred: We prefer that more job training opportunities be available to the DD in private industry, in government, and in sheltered workshops and, to the extent possible, these opportunities be provided within or near the community. I also prefer that programs not only emphasize adequate training for specific and relevant skills, but also develop individual's full potential. Moreover, I prefer more complete client evaluation and follow-up services, more effective cooperation among the agencies involved in vocational training, and more funds for subsidizing client training.

24.0 Job Opportunities for the DD

24.1 What is: There are insufficient opportunities for the adult DD to be employed; most who are employed hold jobs that earn only minimal wages.

What is preferred: We prefer that the DD be given the opportunity to become taxpayers instead of tax burdens... that potential employers be made aware that the DD are capable of holding a job...that an advocate go with the DD to act as a liaison between the employer and the DD... that, in those cases when the adult DD earns wages at a level below those necessary for an adequate income, an income supplement be provided...and that, to the extent possible, legislation require affirmative action for the DD: for example, in some cases, it may be feasible to require that one of each 25 work stations be reserved for DD workers.

24.2 What is: Job opportunities for trained DD are very scarce. Although sheltered workshops are available, they rarely provide opportunities for permanent employment. There is virtually no attention paid to job development or job recruitment which results in minimal job placement of trained DD. As one example, there is little employment of the trainable mentally retarded beyond high school. Moreover, employers don't seem to understand which jobs can be performed adequately by the DD, and there is no centrally located center that is able to evaluate the vocational abilities of individual DD and help them find jobs by serving as a liaison with potential employers.

What is preferred: We prefer that every trained DD be able to find a job; that local cities appraise and use the DD (especially the mentally retarded) in their labor markets; that employers learn to select jobs that are suitable for each individual; that a centrally located employment service for the DD be available; and that a program of permanent -- that is, long-term -- sheltered workshops be instituted.

24.3 What is: Existing sheltered workshops and activity centers are too few in number and/or too limited in number of work stations to accommodate the DD who might benefit from such facilities, e.g., the severely mentally retarded.

What is preferred: We prefer that there be an increase in the number of such facilities and in the identification and development of additional work stations within existing facilities...furthermore, that there be a hierarchy of options available within such facilities for sheltered workshops, ranging from sheltered work or activity to transitional work to outside work experience.

24.4 What is: Job opportunities are extremely limited for all the DD; it is especially hard to find jobs that are even slightly rewarding or that pay adequate wages. In private industry, DD workers are not accepted for many reasons, such as their inability to compete with "normal" workers, a lack of understanding on the part of employers, poor efforts to create new jobs, and the inflexibility of labor and insurance regulations. In the public sector, there is a shortage of all kinds of sheltered workshops.

What is preferred: We prefer that the disproportionately high rate of unemployment among the DD be substantially reduced. There should be organized efforts to help the DD identify and obtain jobs (e.g., through job placement and vocational counseling services); to help potential employers understand the DD and develop a variety of jobs and pay scales for them; and to work for liberalized regulations. We also prefer the establishment of more sheltered workshops (especially those operating on a proprietary basis), with more training grants and more adequate pay for employees.

24.5 What is: Many cerebral palsied individuals find it difficult to get and hold jobs. For all DD, there is no interim job step between sheltered workshops and regular job employment. And for many moderately and mildly retarded adults, the unavailability of insurance seriously limits their opportunities for employment.

What is preferred: We prefer that there be earlier and more vocational counseling, training and placement for the cerebral palsied during and after high school...that an interim step be provided by private industry between sheltered workshops and full-time employment...and that employment insurance be available to those adults who are moderately or mildly retarded.

25.0 General Education Programs for DD Children

25.1 What is: Educational programs for the DD are limited and inadequate. For example, basic education programs are limited in the Four-County area. Some MR's are not in school, but are on waiting lists for special education classes. Adequate public education programs for children with uncontrolled seizures are not available. There is a lack of public education programs (particularly pre-school) for the multihandicapped. And there are few infant education programs (birth to 2 years).

What is preferred: We prefer that educational programs for all DD be available...that basic education programs be expanded in local school districts...that there be adequate public education programs for children with uncontrolled seizures...that there be educational programs for the multihandicapped...that there be training programs for DDs aged 18-21...and that there be education programs for pre-school DD children.

25.2 What is: There are only limited educational programs in our community for all DD children. Most of these programs segregate DD pupils into special classes (which isolates them from regular school programs and stigmatizes them as "different") or put children of too broad an age range or incompatible disorders together in one class. Furthermore, curriculums are not sufficiently individualized, and pupil records are poorly kept.

What is preferred: We prefer that all DD children receive a full-time, publicly supported education. This may involve both special classes and integration into regular classes, with specially trained resource teachers, individualized curriculums, and methodically kept pupil records.

26.0 Physical Education Programs for DD Children

26.1 What is: The physical education of DD children is often neglected. Automatic P.E. exemptions for children with motor disorders are the rule in many public schools, while special schools sometimes do not even provide P.E. programs.

What is preferred: We prefer that all DD children have the opportunity to participate in physical education programs, whether they are in public or special schools.

27.0 Educational Programs for DD children With Special Learning Disabilities

27.1 What is: DD children with special learning problems, such as speech or language deficiencies, do not receive adequate services in our public schools. For example, the availability of speech therapy is very limited. Moreover, many of the DD are unable to read or even recognize words that are important for social or vocational survival. Furthermore, they are frequently unable to communicate effectively with another person, either verbally or nonverbally.

What is preferred: We prefer that more programs be provided for DD children with special learning problems. These programs should include more speech therapy and individualized reading programs, with a minimum goal of teaching the child to recognize socially and vocationally important words. We would also like the DD who lack skills in verbal and nonverbal communication to have such training.

28.0 Educational Programs for TMR Children

28.1 What is: There are inadequate educational programs, facilities, and trained personnel for all the TMR. Many are not being served, although they are eligible, especially those from rural communities who have no transportation. Existing programs are hampered by over-crowded classrooms, by the inclusion of too wide an age range of pupils, and by the lack of an adequate pre-vocational curriculum focusing on functional academic and self-help skills.

What is preferred: We prefer that more TMR children be served by special educational and prevocational programs and by regular visits with trained specialists, such as speech therapists. Moreover, we prefer that transportation to these programs and services be available, particularly in rural areas. Finally, we prefer that programs emphasize self-help skills and functional reading and writing, and that better materials and methods for TMR instruction be developed.

29.0 Educational Programs for EMR Children

29.1 What is: Educational programs for the EMR, if they exist at all, tend to place too much emphasis on traditional academics and neglect the more critical areas of life adjustment. This is especially true at the junior and senior high school level, where insufficient efforts are focused on vocational, pre-vocational, and social adjustment skills. At the elementary and intermediate levels, basic skills, particularly reading, are often not taught effectively. Furthermore, class sizes and age ranges within classes are frequently too large.

What is preferred: We prefer that appropriate educational programs be available for all EMR's in our community; that these programs include both academic and life skills (with an emphasis on the latter); that programs at the secondary level emphasize vocational, pre-vocational, and social skills (including sex education and on-the-job training); and that programs at the primary and intermediate levels teach basic skills in smaller classrooms with more homogeneous age groupings.

30.0 Social and Recreational Activities for the DD

30.1 What is: There are currently in our region no activity centers, special recreational facilities, or special programs designed to provide the developmentally disabled of all ages with opportunities for social interaction, counseling, continued education, recreation, or just a variety of kinds of physical exercise.

What is preferred: We prefer that in addition to schools and school programs there be activity centers in each locality large enough to support them -- ideally, in all major towns in our region; that there be community-wide socialization services, special recreational programs and facilities, and ample opportunities for the DD to engage in physical exercise; and that organizations throughout the region make a point of inviting and integrating the DD in their own social activities.

30.2 What is: The social and recreational needs of the DD are not being adequately met. Specifically, the DD are socially isolated within the community by being separated from normal participation in clubs and recreational facilities, and by the lack of activity centers, special recreational facilities, or other programs designed to provide them with varied, meaningful activities. Those who are too old to have access to school activities or who are less able particularly need stimulating programs.

What is preferred: We prefer that the DD be integrated into the social structure of the community as much as possible. The community should develop social programs and recreational facilities (such as clubs and activity centers) that would serve the DD and also allow them contact with members of the wider community. There should be special provision for older DDs and for the less able.

31.0 Counseling and Training Services for Families of the DD

31.1 What is: Some parents find it difficult to acknowledge or accept their DD children, others are apathetic toward their children's conditions, and nearly all worry about how to provide supervised long-term security (financial, physical, and emotional) for their children, particularly if they are severely disabled. Help for parents who want their children to remain at home rather than be institutionalized is either unavailable or inadequate. For example, there is a general lack of counseling services for parents of the DD; there is a particular lack of counseling services for helping handle matters of family stress associated with severe (terminal) illnesses of multiply handicapped children. In addition, there is a lack of follow-up services and social advocacy programs for parents, there are few educational seminars for parents to learn more about their childrens' legal rights and social opportunities and about how to stimulate and work with them; and there is little research conducted on the psychological stresses upon parents of the DD.

What is preferred: We prefer that there be more help available to parents of the DD to help them accept and deal with their children -- more frequent and expert counseling services, on both an emergency and on-going basis; more parental seminars and training sessions to develop parental knowledge and skills; and more research on the psychological problems and stresses facing parents of the DD.

31.2 What is: Many parents of the DD do not provide their children with the kinds of early experiences conducive to good mental, social, emotional and physical development. Rather, they inhibit independence and self-sufficiency by withdrawing interest, over-protecting, or failing to expose their children to "real-life" situations. In the extreme, families of the DD ignore the abilities or limitations of their children and may refuse to cooperate closely with those able to provide services.

What is preferred: We prefer that (beginning with identification of a child's disability) families of the DD receive ongoing professional guidance to help them understand the disability and aid in its treatment. In addition, we prefer that families either expose their DD children to more real-life situations or else help them find alternative living arrangements that encourage their self-sufficiency, and that families cooperate more closely with service agencies.

31.3 What is: Programs and facilities for training parents of the DD about available services and about skills and strategies for dealing with the DD child are limited or nonexistent.

What is preferred: We prefer that there be coordinated parent education programs in all areas of the county to provide knowledge of services and training for dealing with the DD children.

31.4 What is: Most families of the DD need professional assistance. However, there is little guidance and training available to help parents understand their children and lead them to fuller lives. Parents are not given sufficient individualized training in teaching DD children or in handling behavior problems. Moreover, there is a lack of professional counseling services to help families cope with specific problems or develop long-range plans.

What is preferred: We prefer that community-based programs be developed to provide families with the training they need to cope with the care and problems of their DD members. Parents should have information about what is available for the DD and individual instruction (from parent training specialists) in how to teach their children. In addition, we prefer that professional counselors be available to help parents (through classes, discussion groups, or group counseling sessions) improve family life and develop their DD child.

31.5 What is: There is little or no professional counseling help available or readily accessible to either the DD themselves or their families: little or no help in "life-span planning;" little counseling for individuals and families with epilepsy; little help in family crises (marital or sibling).

What is preferred: We prefer that there be much more counseling available to the DD and their families...that there be long-range counseling...and that there be more consultative help available to all who care for the DD.

32.0 Financial Assistance to Families of the DD

32.1 What is: Families of the DD -- especially of low and middle income -- are burdened with financial problems. Comprehensive insurance is expensive and limited. Many expensive services and equipment are not covered by present insurance coverage.

What is preferred: We prefer that services be made directly available to all DDs without cost...that there be financial assistance for treatment...or that there be monitary "disaster" relief for particularly expensive services.

32.2 What is: Families are overburdened with the high costs of special services (medical treatment, prescription diets, etc.) for their DD members. They must sometimes pay for services that are free for "normal" children, and there is little assistance for middle-income families. Foster DD children are not considered adoptable because of the unrelieved expenses of rearing them, nor are their foster parents adequately compensated.

What is preferred: We prefer that families be relieved of the heavy expenses of providing special care for DD members. Services should be available to all the DD, without costing more than they do for "normal" children, and families (including foster and adoptive parents) should have more financial relief, regardless of their income.

33.0 Respite Services for the DD and Their Families

33.1 What is: There is inadequate part-time or respite care for all ages of the DD. Specifically, there are too few babysitting, nursing, or homemaking services for families with live-in DD members, which often prevents the rest of the family from working, responding to emergencies, or obtaining periodic relief from their full-time care responsibilities. Furthermore, there are few community residential facilities for short-term respite care of the DD. What is available is frequently too expensive. Without these services, families must often place DD members in institutions.

What is preferred: We prefer that more professional part-time care be available, including babysitting, nursing, and homemaking services. In addition, we prefer that local facilities be available for short-term, residential respite care.

33.2 What is: There is currently in our region limited help available to provide personal care for those DDs who are homebound or homefast and to relieve persons and families of the DD who need to provide constant, round-the-clock care of their developmentally disabled family members. There are, for example, only a limited number of babysitters who can assist the families of the DD as well as the DDs themselves, and there are no speech therapists who can provide regular home services for those who are developmentally disabled.

What is preferred: We prefer that there be more help available to care for homebound DDs; that respite care be available to the families of DDs; that babysitters be especially trained to handle the needs of the DDs; and that speech therapists be available to provide regular home services to those DDs who are homebound or homefast.

33.3 What is: There is inadequate part-time care, on either a regular or respite basis, for all ages of DD. Specifically, there are too little voluntary or no cost baby-sitting or homemaking services available to families of the DD, which often prevents them from being able to work, respond to emergencies, or periodically be relieved of hourly-daily responsibilities in the care of DD persons within the family. A central referral system for these services is not available.

What is preferred: We prefer that local services for part-time care be established, including provision of trained personnel who can come to the homes of the DD for baby-sitting and homemaking services.

33.4 What is: It is difficult for families of the DD to obtain respite from their normal responsibilities or in times of crisis. There are, for example, limited day-care services for DDs in our region.

What is preferred: We prefer that there be more respite care available in the county...that there be, for example, day care services for DDs available in all areas of the country.

A Complete List of the Eleven Expanded Problem Statements Adopted by the Oregon State Council for Use in the State Plan

FIRST PRIORITY

COORDINATION OF SERVICES FOR THE DEVELOPMENTALLY DISABLED

What Is:

There are currently 8 service coordinators in Oregon serving 12 counties (44% of Oregon's population). The service coordinators: (1) assist the developmentally disabled and their family in obtaining and utilizing existing services; (2) disseminate information to the developmentally disabled and general public; (3) develop and maintain:
(a) a catalogue of services available to the developmentally disabled;
(b) a local identification system of the developmentally disabled;
(c) local data on the unmet needs of the developmentally disabled and on services provided for input into a statewide information system;
(4) advocate and facilitate program development; and (5) provide follow-along services to the developmentally disabled.

What is Preferred:

We prefer continuation of the existing services provided by the service coordinators and expansion in the following areas:

- prefer to provide Oregon with full geographic coverage by service coordinators;
- prefer combination of state and local funding for the service coordinator positions;
- prefer stronger utilization and involvement of service coordinators in planning development and coordination of local programs for the developmentally disabled;
- prefer that service coordinators be fully responsible for the community placement and follow-along of all institutional residents.

SECOND PRIORITY

PERSONAL RIGHTS OF THE DEVELOPMENTALLY DISABLED

What Is:

The right of the developmentally disabled to receive compensation for work performed is often neglected in vocational and institutional settings. The developmentally disabled may be denied use of their personal allowances, be kept in institutions against their best interest, or have behavior controlled with medication in lieu of suitable programs.

What is Preferred:

We prefer that developmentally disabled individuals be protected against exploitation. Where a person is unable to determine his rights, protection should be provided by guardianship and advocacy programs. The Declaration of Rights of the Mentally Retarded as adopted by the United Nations and International Congress on Mental Retardation should apply in all cases.

THIRD PRIORITY

PRE-SCHOOL FOR THE DEVELOPMENTALLY DISABLED

What Is:

There are too few direct education, training and therapy services available for the developmentally disabled 0-6 years old. Parent counseling and training programs to support direct services received by the child are often not considered an integral part of pre-school programs. Existing early education programs separate the handicapped from non-handicapped -- if the education programs accept the handicapped at all. Home infant stimulation programs are usually not considered an integral part of pre-school programs.

What is Preferred

We prefer that there be more programs to provide direct early services to the developmentally disabled children 0-6 years old. These programs should be integrated as much as possible with "regular" pre-school programs, but should focus on early intervention in the areas of developmental as well as academic difficulties, plus providing training in basic self-care, social adjustment and language development. In addition, parental education, training, and home infant stimulation programs should be made an integral part of each and every pre-school program.

FOURTH PRIORITY

SCREENING FOR EARLY IDENTIFICATION OF THE DEVELOPMENTALLY DISABLED

What Is:

At present, screening for early identification of developmentally disabled individuals is inadequate. Further, comprehensive diagnostic and evaluation procedures are often unavailable for those who have been identified.

What is Preferred:

We prefer that every individual have the advantage of a broad based screening program within a reasonable distance of his home. Those individuals identified as having a possible developmental disability should be seen promptly and, if necessary, included in a system of coordinated services.

FIFTH PRIORITY

FUND FOR PROVIDING SERVICES FOR THE DEVELOPMENTALLY DISABLED

What Is:

a) Funds for services to the developmentally disabled are inadequate.

b) Some funds allocated for the developmentally disabled are lost in the general fund of some agencies.

c) Agencies and services are frequently ineffective or redundant.

d) Funds are often limited by categorical restrictions.

e) Mechanisms for funding are clumsy and ineffective, cause confusion in agencies and discourage local services.

What is Preferred:

a) We prefer more local, state, and federal funds for improving programs.

b) We prefer that specially designated funds be used only for their intended purpose.

c) We prefer that interagency planning for use of developmental disabilities funds be encouraged.

d) We prefer that funds for developmental disabilities be developed with as few restrictions as possible on types of developmentally disabled persons eligible.

e) We prefer that funding sources provide suitable time and support to encourage providers of service.

SIXTH-SEVENTH PRIORITY

ALTERNATIVE LIVING ARRANGEMENTS FOR THE DEVELOPMENTALLY DISABLED

What Is:

Alternative living arrangements for the developmentally disabled are extremely limited. On the one hand, there is inadequate part-time or respite care for all ages of the developmentally disabled. Specifically, there are too few baby sitting, nursing or homemaking services for families with live-in developmentally disabled members, which often prevent the rest of the family from periodic relief from their full-time care responsibilities.

On the other hand, there is a lack of group homes, foster homes, half-way houses, and other noninstitutional living facilities which provide care and independent living experiences for the developmentally disabled, on either a part- or full-time basis. Existing facilities are often inconveniently located, and are not prepared to deal with certain disabilities (such as emotional disturbance or multiple handicaps), and usually do not provide regular social or educational activities. In addition, their supervisors are often poorly trained and badly paid.

What is Preferred:

We prefer that a continuum of alternatives for residential care be available for all ages of the developmentally disabled. At one end of the continuum, we prefer that professional part-time care be available, including babysitting, nursing, and homemaking service, both in and out of the home. We also prefer that a variety of community based homelife living arrangements are available on a full-time basis so that the developmentally disabled can live as independently and actively as possible. These facilities should be centrally located and integrated with off-site community educational, vocational, recreational and transportation services. Finally, we prefer that adequate pay be available for well trained and qualified individuals to work in facilities meeting established standards of care.

SIXTH-SEVENTH PRIORITY

COUNSELING AND TRAINING SERVICES FOR FAMILIES OF THE DEVELOPMENTALLY DISABLED

(a) COUNSELING

What Is:

Some parents find it difficult to acknowledge or accept their DD children, others are apathetic toward their children's conditions, and nearly all worry about how to provide supervised long-term security (financial, physical, and emotional) for their children, particularly if they are severely disabled. Help for parents who want their children to remain at home rather than be institutionalized is either unavailable or inadequate. For example, there is a general lack of counseling services for parents of the DD; there is a particular lack of counseling services for helping handle matters of family stress associated with severe (terminal) illnesses of multiply handicapped children. In addition, there is a lack of follow-up services and social advocacy programs for parents, there are few educational seminars for parents to learn more about their childrens' legal rights and social opportunities and about how to stimulate and work with them; and there is little research conducted on the psychological stresses upon parents of the DD.

What is Preferred:

We prefer that there be more help available to parents and family of the developmentally disabled to help them accept and deal with their children -- more frequent counseling services on both an emergency and on-going basis to include life span planning, and more research on the psychological problems and stresses of parents and families of the developmentally disabled.

(b) TRAINING

What Is:

Programs and facilities for training parents and family of the developmentally disabled about available services and about skills and strategies for dealing with the developmentally disabled child are limited.

Many parents of the DD do not provide their children with the kinds of early experiences conducive to good mental, social, emotional and physical development. Rather, they inhibit independence and self-sufficiency by withdrawing interest, over-protecting, or failing to expose their children to "real-life" situations. In the extreme, families of the DD ignore the abilities or limitations of their children and may refuse to cooperate closely with those able to provide services.

What is Preferred:

We prefer that there be coordinated parent education programs in all areas of the state to provide knowledge of services and training for dealing with developmentally disabled children. We prefer that community-based programs be developed to provide families with the training they need to cope with the care and problems of their developmentally disabled members. Parents should have information about what is available for the developmentally disabled, and individualized and group instruction (from parent training specialists) in how to teach their children in the areas of language, motor development, practical living skills, and behavioral adjustment.

EIGHTH PRIORITY

SERVICES FOR POST-SCHOOL DD ADULTS

What Is:

There are gaps in the lifespan of service for the post-school age DD. Gaps occur in at least the following areas in the post-school age:

a) Activity centers
b) Sheltered workshops
c) Community living facilities
d) Recreation and leisure time activities
e) Geriatrics

What is Preferred:

We prefer that a continuity of services exist in Oregon beyond the school age for all DDs to include the availability of:

a) Workshops or activity centers
b) Community living accommodations
c) Recreation and leisure time activities.

NINTH PRIORITY

JOB TRAINING AND EMPLOYMENT FOR THE DD

a) What Is:

It is difficult to secure work experience training and adequately paid and suitable jobs for the DD.

What is Preferred:

We prefer that all DD persons have work experience training at 16 to 21 years of age and that all adults needing work training receive it too. Programs which provide funds for vocational training such as Vocational Education Act, Vocational Rehabilitation Division cooperative agreements, and OJT-NARC funds should be better utilized and expended to serve the DD, Workman's Compensation and Bureau of Labor regulations should be broadened to encourage employers to participate in work training programs.

b) What Is:

Vocational training programs for the DD are extremely limited. Existing training programs are often irrelevant and/or non-redemptive; many exclude certain disability groups or depend on unreliable "contract work" with private industry; and many are not suited to the needs or talents of the individuals involved.

What is Preferred:

We prefer that more job training opportunities be available to the DD in private industry, in government, and in sheltered workshops and, to the extent possible, these opportunities be provided within or near the community. We also prefer that programs not only emphasize adequate training for specific and relevant skills, but also develop the individual's full potential. Moreover, we prefer more complete client evaluation and follow-up services, more effective cooperation among the agencies involved in vocational training, and more funds for subsidizing client training.

c) What Is:

There are insufficient opportunities for the adult DD to be employed; most who are employed hold jobs that earn only minimal wages.

What is Preferred:

We prefer that the DD be given the opportunity to become taxpayers instead of tax burdens...that potential employers be made aware that the DD are capable of holding a job... that an advocate go with the DD to act as a liaison between the employer and the DD...that, in those cases when the adult DD earns wages at a level below those necessary for an adequate income, an income supplement be provided...and that, to the extent possible, legislation require affirmative action for the DD: for example, in some cases, it may be feasible to require that one of each 25 work stations be reserved for DD workers.

d) What Is:

Job opportunities for trained DDs are very scarce. Although sheltered workshops are available, they rarely provide opportunities for permanent employment. There is virtually no attention paid to job development or job recruitment which results in minimal job placement of trained DDs. As one example, there is little employment of the trainable mentally retarded beyond high school. Moreover, employers don't seem to understand which jobs can be performed adequately by the DD, and there is no centrally located center that is able to evaluate the vocational abilities of individual DDs and help them find jobs by serving as a liaison with potential employers.

What is Preferred:

We prefer that every trained DD be able to find a job; that local cities appraise and use the DD (especially the mentally retarded) in their labor markets; that employers learn to select jobs that are suitable for each individual; that a centrally located employment service for the DD be available; and that a program of permanent -- that is, long-term -- sheltered workshops be instituted.

e) What Is:

Existing sheltered workshops and activity centers are too few in number and/or too limited in number of work stations to accommodate the DD who might benefit from such facilities, e.g., the severely mentally retarded.

What is Preferred:

We prefer that there be an increase in the number of such facilities and in the identification and development of additional work stations within existing facilities... furthermore, that there be a hierarchy of options available within such facilities for sheltered workshops, ranging from sheltered work or activity to transitional work to outside work experience.

f) What Is:

Job opportunities are extremely limited for all the DDs; it is especially hard to find jobs that are even slightly rewarding or that pay adequate wages. In private industry, DD workers are not accepted for many reasons, such as their inability to compete with "normal" workers, a lack of understanding on the part of employers, poor efforts to create new jobs, and the inflexibility of labor and insurance regulations. In the public sector, there is a shortage of all kinds of sheltered workshops.

What is Preferred:

We prefer that the disproportionately high rate of unemployment among the DD be substantially reduced. There should be organized efforts to help the DD identify and obtain jobs (e.g., through job placement and vocational counseling services); to help potential employers understand the DD and develop a variety of jobs and pay scales for them; and to work for liberalized regulations. We also prefer the establishment of more sheltered workshops (especially those operating on a proprietary basis), with more training grants and more adequate pay for employees.

g) What Is:

Many cerebral palsied individuals find it difficult to get and hold jobs. For all DDs, there is no interim job step between sheltered workshops and regular job employment. And for many moderately and mildly retarded adults, the unavailability of insurance seriously limits their opportunities for employment.

What is Preferred:

We prefer that there be earlier and more vocational counseling, training and placement for the cerebral palsied during and after high school...that an interim step be provided by private industry between sheltered workshops and full-time employment...and that employment insurance be available to those adults who are moderately or mildly retarded.

TENTH PRIORITY

TRAINING FOR THE DD WITH RESPECT TO BASIC LIVING SKILLS

What Is:

DD individuals often lack sufficient skills to prepare them for independent or semi-dependent living in the community.

What is Preferred:

We prefer to establish basic training programs in self-help skills, social skills and the ability to manage financial affairs.

ELEVENTH PRIORITY

GENERAL EDUCATION PROGRAMS FOR DD CHILDREN

What Is:

Educational programs for the DD are limited and inadequate. Some DD children are not in any educational classes. Many existing programs inappropriately segregate DD pupils into special classes which isolate them from regular school programs, or place students of incompatible disorders together in one class. Furthermore, many curriculums are not sufficiently individualized and public records are poorly kept. Few educational programs include pre-school and the 18-21 age group.

What is Preferred:

We prefer that all DD children from 18 months to age 21 receive a full-time, publicly supported education adequate to each individual need.
(Reference Pennsylvania Decision)